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COMPLIANCE WITH CHILDHOOD LEUKEMIA TREATMENT IN INDONESIA

INFLUENCE OF SOCIO-ECONOMIC STATUS ON TREATMENT REFUSAL OR ABANDONMENT

Saskia Mostert

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VRIJE UNIVERSITEIT

COMPLIANCE WITH CHILDHOOD LEUKEMIA TREATMENT IN INDONESIA

Influence of socio-economic status on
treatment refusal or abandonment

ACADEMISCH PROEFSCHRIFT

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promotoren: prof.dr. A.J.P. Veerman
prof.dr. Sutaryo

For the ones
who do not speak

Tracy Chapman

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Addendum: SOME CULTURAL BACKGROUNDS

For a physician
the human body is the object of study
For a person seeking wisdom
the human mind

Epictetus

I. INTRODUCTION

1.1 GENERAL INTRODUCTION

Acute lymphoblastic leukemia (ALL) is the most common malignancy of childhood and is still a major cause of childhood mortality.

ALL is universally treated according to prolonged chemotherapeutic schedules, referred to as protocols. **Compliance** with these protocols can be described as "acting in accordance with the rules of the prescribed treatment schedules". It is noteworthy that adherence failure is not restricted to patients and parents, but can also concern physicians.

In childhood ALL complete remission, accomplished during the induction and consolidation components of therapy, is usually followed by relapse unless patients receive extended oral maintenance treatment at home during two years.

When patients relapse unexpectedly, one of the causes can be failure of this maintenance treatment. There is growing suspicion that non-compliance may be a more important reason than is generally appreciated (1).

Non-compliance forms a continuum from the sporadic lapse to total withdrawal.

Non-compliance is an ancient problem. Hippocrates already warned medical doctors to *"keep watch also on the fault of patients, which often make them lie about the taking of things prescribed"*. However, after passage of centuries, non-compliance with medication still remains poorly understood and a source of frustration (2).

We know, based on experience with astma, tuberculosis and diabetes, that young patients frequently fail to follow significant therapeutic schedules or diets. Therefore it is illogical to suppose that all children with leukaemia will reliably take tablets on a daily basis during two years. This holds especially truth because ALL patients are usually in normal health after achieving complete remission and suffer no immediate consequences when doses of drugs are missed. Nevertheless, pediatric oncologists ignored the warnings and assumed good compliance for a long time, simply because leukemia is a profound life threatening illness (1).

Studies estimate that in developed countries 10 to 40% of young children with ALL on oral maintenance chemotherapy and 50 to 60% of teenagers do not reliably take all their pills (2-11). Non-compliance may be one of the reasons why the outlook for teenagers with leukaemia is worse than for younger children where other risk factors are the same. The few studies conducted in developing countries or in ethnic minority groups residing in developed countries mention that non-compliance is even a bigger problem in people from the third world. Especially the number of drop-outs is extensive in developing countries (12-17).

Non-compliance implicates that children on outpatient chemotherapy may develop recurrence of leukemia just because they do not reliably take their drugs and are thereby undertreated or even not treated at all. Poor compliance in less affluent countries can also be caused by financial circumstances, for instance because the family is not able to buy all the prescribed medication.

Dose escalation in patients who appear “tolerant”, yet in reality are “non-compliant” with chemotherapy can be dangerous. When these children suddenly do comply and take an inflated dose of medicine, severe myelosuppression might result (2,3).

Also wider implications can be ascribed to the problem of non-compliance. Treatment for ALL generally takes place within the context of trials. These trials assess the efficacy of different protocols without taking compliance into account. This may give rise to misleading results or inconsistent response rates to therapy and affect future chemotherapeutic regimen.

Poorer prognosis in childhood ALL in developing countries and in ethnic minority groups in developed countries is partly due to deaths during remission. Studies reveal that this poorer survival is not only caused by differences in clinical presentation, tumor biology or undernutrition, but poor compliance associated with poverty might be an important cause (12-15, 18-21).

Compliance is a complex and multifaceted issue. Adherence to a medical protocol is determined by a variety of factors related to the patient, disease, health-care providers and treatment characteristics.

The compliance determinant concerning therapy of childhood ALL has currently gained greater significance as treatment is administered with curative, rather than palliative intent (5,6,9).

If non-compliance could be circumvented both in developed and developing countries, maybe long-term disease free survival would be increased and this achievement is also economically attractive. Oral chemotherapy at home is inexpensive whereas treatment for relapsed ALL is very costly and not curative in most patients. The tendency to more intensive, toxic and expensive therapeutic protocols might also be slowed down (1).

Compliance is still poorly understood and requires further investigation. Profound research on compliance in a developing country can give us an important insight in its nature and may help us design strategies to improve compliance. On a worldwide scale, this may simplify and reduce the cost of treatment and eventually lead to more children receiving potentially curative treatment.

I.2 SPECIFIC INTRODUCTION: AIMS AND OUTLINE OF STUDY

This study on compliance has been conducted in the Dr. Sardjito Hospital in Yogyakarta, situated on the island Java in Indonesia. Dr. Sardjito Hospital is a tertiary care referral state hospital of the Gadjah Mada University.

The longstanding close collaboration or "twinning project" between pediatric hemato-oncology departments of VU University Medical Center in the Netherlands and Dr. Sardjito Hospital in Indonesia dates back to 1992 (22). Twinning projects attempt to share knowledge, improve treatment and increase survival of childhood cancer in resource poor countries (23).

The aims of this study are:
1) To examine the influence of socio-economic status on childhood ALL treatment and treatment refusal or abandonment in a developing country.
2) To investigate parental experiences during childhood ALL treatment and their reasons to refuse or abandon treatment.
3) To determine whether a parental education program increases the access to donated chemotherapy and decreases treatment refusal or abandonment.

Part One focuses on the actual study. However, we realize that in order to understand compliance in a society, it is essential to gain more insight into the history and culture of the people inhabiting that country. Culture influences not only the conduct of doctors, patients and relatives, but also the perception and experience of diseases and thereby the provided and taken treatment. For these reasons, we provide in **Part Two** background information about Indonesia and Java. We discuss Indonesian history, ethics, language, critical perspectives by social scientists and commentators, and the problem of corruption.

Part One contains the following chapters:
In **Chapter 1** a retrospective medical records study (1997-2002; n=164) was performed and open exploratory interviews with 21 health-care providers and 17 parents were conducted to assess the influence of parental socio-economic status on childhood leukemia treatment in Indonesia. We found that although poor and prosperous patients received the same protocol, actual implementation of treatment and treatment results differed significantly between poor and prosperous patients. Structured parental education about leukemia, its treatment and about the possibility of receiving donated chemotherapy was lacking.
Based on these findings a structured parental education program about leukemia, its treatment, donated chemotherapy and compliance was designed. Starting from 2004 this program has been provided to all parents. The program consisted of a video-presentation in hospital, information-booklet, audiocassette, DVD, procedures for informed-consent, statement of understanding for donated chemotherapy and a complaints-mechanism.
In **Chapter 2** a self-administered semi-structured questionnaire was filled in by 102 health-care providers (69 doctors, 28 nurses, 2 psychologists, 2 hematology technicians, 1 administrator) to determine whether parental socio-economic status influences beliefs, attitude and behavior of health-care providers treating childhood leukemia. We concluded that beliefs, attitude and behavior of health-care providers toward poor versus prosperous patients appeared to differ and may contribute to the

immense drop-out rate and slight chances of survival among poor leukemia patients in developing countries.

Chapter 3 reports about a cross-sectional study, in which 51 parents were interviewed by independent psychologists using semi-structured questionnaires. The objective was to examine the access of parents to donated chemotherapy, after introduction of the structured parental education program. Four patients had health-insurance and did not need donated chemotherapy. Access to donated chemotherapy was improved: 46/ 47 patients (98%) received donations, as opposed to 16% in the past. We concluded that structured parental education improved access to donated chemotherapy. Outreach-programmes may benefit from this approach. This may enable more patients from poor socio-economic backgrounds in developing countries to receive aid and achieve cure.

Chapter 4 describes a study in which 37/40 families (93%), whose children had refused or abandoned ALL treatment, were home-visited and interviewed. Aims of the study were to analyze the parents' reasons of abandonment and to ascertain the fate of their children. We concluded that reasons for abandonment were complex. Most parents mentioned several reasons. Financial and transportation difficulties, belief of ALL in-curability, experience of severe side-effects and dissatisfaction with health-care providers were important considerations. Of the 37 patients who refused or abandoned treatment, 26 (70%) children died, and 11 (30%) children were still alive.

In **Chapter 5** interviews were conducted with 51 parents by independent psychologists using semi-structured questionnaires, to assess socio-economic, treatment-related, and psychological experiences during leukemia treatment. We concluded that the socio-economic impact of leukemia treatment was profound. Communication between parents and doctors requires improving. The role of the parent organization was insignificant and must be ameliorated.

Chapter 6 reports that medical records of 283 children with ALL were reviewed, in order to compare childhood ALL treatment outcome before (1997-2002; n=164) and after (2004-2006; n=119) introduction of the parental education program. We concluded that after introduction of the education program, poor families received structured information about leukemia, its treatment, and donated chemotherapy for the first time. A significant decrease in treatment refusal and increase of event-free survival of poor patients occurred. To improve survival significantly in the overall population, it is important that toxic-death and treatment abandonment decrease as causes of treatment failure. Improvement of knowledge, skills and communication of doctors is required to manage treatment toxicity and prevent treatment abandonment. Treatment intensity should be matched with possibilities of supportive-care.

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THE STUDY

The world is not changed by logic
but by emotion

Plastic Surgery Outreach Program "Operation Smile"

I. PEDIATRIC ONCOLOGY PROJECTS IN DEVELOPING COUNTRIES

I.1 JUSTIFICATION

Most children live in developing countries. In developing countries important improvements regarding the treatment of common fatal illnesses, like diarrhea and pulmonary infections, have been achieved. Consequently, cancer will become a more significant cause of childhood mortality in countries with limited resources (1).

Not only medical but also socio-economic hardships encountered in developing countries hinder the development of pediatric oncology. The restricted finances available for health care and the urgent public health issues as water supply, sanitation, nutrition, infectious diseases, immunisation, schooling and housing, gives pediatric oncology understandably and correctly a low priority. Pediatric cancer is not only rare but its treatment is also expensive. Inexpensive interventions for common health issues will bring greater benefit to the community (1-3).

Yet, many children die from cancer in developing countries for various reasons. Their illness generally happens to be in a more advanced state at the time they seek medical help, chemotherapy is either not available or too expensive for most parents and pediatric oncology expertise and adequate facilities are lacking. One might say that the child suffering from cancer is as much entitled to life as a child with diarrhea or pneumonia. Therefore the development of less intensive, less toxic and cheaper therapies is desperately needed (1).

However, the practice of pediatric oncology is rightly not a top priority in developing countries. But investing in its development, without depriving the more crucial public health programs, can benefit both patients as well as the medical scientific world (1).

Establishing pediatric oncology in less developed nations can best be accomplished by longstanding partnerships between hospitals in developed and developing countries. Through such twinning projects expertise and technology can be shared. These cooperations could annually save the lives of thousands of children. In the future expansion of their capability can coincide with the expected economic development and increased significance of pediatric cancer as a mortality cause. Studies conducted through pediatric oncology projects in developing countries will increase our knowledge of malignancies throughout the world. This can help us to improve the survival rates in children with cancer more rapidly (1).

I.2 SPECIFIC PROBLEMS

Pediatric oncology units in developing countries face specific problems that should be accounted for if one is willing to make a difference. The main problems evolve from poverty and large population sizes. Lack of education and little awareness of health issues delay the seeking of medical help. Consequently, the children have a more

advanced stage of cancer at diagnosis. The poor parents are barely able to pay for the medical care, particularly the expensive prolonged care and costly drugs required for pediatric cancer. Due to the lacking knowledge regarding health problems, especially regarding rare problems as childhood cancer, parents do not understand why extended therapy is necessary as soon as their child appears to be healthy again. Centers specialised in pediatric cancer are scarce, making their access difficult or impossible for less affluent parents as they cannot even afford the transportation costs to reach the distant clinic. Developing countries are confronted with malnutrition and high prevalence of infectious diseases, making the children with cancer more vulnerable and less tolerant of chemotherapy. The numbers of qualified physicians and nurses are far too little for the excessive amount of patients. Their training needs improvement and the used facilities are often not adequate. The chemotherapeutic drugs and antibiotics are in short supply or not available at all. Senior experienced medical doctors are needed (1,4).

Another major problem in developing countries that should be thought of and dealt with is corruption. In developing nations both medical as well as non-medical development projects face the destructive combination of corruption, inefficiency and bad planning. Hereby the assigned funds are immediately threatened to be drained for the wrong purpose, being the benefit of corrupt powerholders. Professor Syed Hussein Alatas compares corruption in this context with a disease; “ If well under control harmless, if not deadly” (5).

I.3 RESEARCH

Twinning projects usually stimulate academic research in the less affluent twin. The most rewarding twinning projects contain also longterm clinical trials in which both partners can become familiar with the encountered difficulties.

Conducting research in developing countries offers various advantages and opportunities. As specialised centers are rare and the young population is extensive, these centers encounter a large number of patients. Clinical trials can therefore be completed in a shorter period of time and may involve only one or a small number of institutions. The less developed nations, with their large gap between the poor and more privileged, offer excellent possibilities to investigate the influence of social, educational and economic backgrounds on compliance. Research needs to focuss on a cheaper, simplified and possibly shorter treatment. The results of these altered regimens on survival will be significant for the development of new therapies in the developed world too. The costs of scientific research in the less affluent twin will be less expensive (1).

I.4 PROTOCOLS

It is not suitable to simply transfer and implement chemotherapy protocols from developed countries to developing nations. Of course the aim is to provide adequate treatment that is able to produce equivalent results. Yet, intensive chemotherapy requires excellent supportive care that is not available. Children who are frequently undernourished or have infections, may respond differently to the toxic medicines.

Also severe drug schedules that are dangerous if not adequately administered, should be avoided as much as possible. Both patients and physicians will more easily fail to comply with complicated and intensive protocols. The latter are usually more expensive and demand larger efforts from nurses and doctors.

In less developed countries it might not only be necessary to alter the intensity but also the duration of therapy. The burden on the poor families is even larger and drugs are either not available or not affordable. Frequently doctors select patients appropriate for therapy on several criteria: standard risk cancer, prosperous family background and supposedly better compliers. Shorter treatment schedules however might allow more children to enter and finish the defined protocols.

The utilised protocols in developed countries might be more intense, toxic, expensive and longer lasting than strictly necessary. As they have proven to give a survival rate of approximately 80% after 5 years it is difficult to alter them for fear of lesser results. In developing countries less intensive, less toxic, cheaper and shorter lasting protocols are required. Longterm clinical trials investigating their effects are essential and could eventually also bring benefit to children in the developed world (1).

I.5 EDUCATION

Developing countries often have low educational standards. Lacking education results in poor knowledge of health issues and little understanding of the necessity to continue with treatment when a child appears well again. Non-compliance and drop-out frequently evolve. Bringing a “cured” child to a clinic does not seem a priority, when the family is struggling to earn a living (1,2,6,7).

Providing education and information about treatment and compliance is crucial. Awareness of the local customs, beliefs and fears is required to adjust the given information and improve cooperation with treatment. In chosing proper sources of education, one should take account of the following. In general illiteracy rates in developing countries are high. Physicians encounter large numbers of patients, giving them little time to provide extended parental education. Besides this, communication between doctors and poor parents is frequently hindered by hierarchical structures that strongly exist in most developing countries (1,4,6).

Written information can bring benefit to parents and patients who can read, but should be supplemented by audiocassettes for those who cannot. Educational films are effective as they save time and the information given is complete. It gives the opportunity to not only let health care providers, but also parents of cured children motivate families to continue therapy. Introduction of informed consent should also pay attention to both written and auditive or visual documentation and the little educational background of most parents (1).

In case of drop-out it is essential to immediately contact patients and parents, ask for their reasons, persuade them to continue by giving information about the necessity of treatment prolongation and financial support where required. This cannot only save the life of their child, but is also important for the follow-up and enables us to provide correct data for the clinical trials that assess the efficacy of treatment. However, one

should realise that contacting defaulting patients and parents is frequently a big enterprise, as parents generally have no phone and may live far from the clinic in rural areas where they are difficult to trace. Therefore installation of an individual or team to detect drop-outs is highly recommended and rewarding (1).

I.6 PARENT ORGANISATION

Strong parent organisations are important in providing good care to cancer patients and their families. Strong parents organisations are however difficult to install, especially in developing countries. There are usually large status differences between physicians and parents. In the existing hierarchy it is commonly not accepted that poor parents take on a leading role and position. As poverty is associated with little education, parents are frequently also not capable to fulfil leadership. Tensions and conflicts can arise when health care providers and parent organisations have opposed interests. Such conflicts may be completely inappropiate in certain cultures. As parents depend on doctors for a good care of their child, this may force them to be silent and raise no unrest. The structure of parent organisations therefore needs to be adapted to the culture. Parent leaders should receive training and doctors should learn that all parties involved eventually will benefit if parents also have a strong position (8).

You cannot change
what you do not acknowledge

II. COMPLIANCE DETERMINANTS

Poor compliance with therapeutic regimens is recognized as a major issue, but physicians have difficulties to identify in advance those patients for whom adherence will be a problem. We will highlight various characteristics concerning patient, family, disease, treatment and health-care providers that determine how well a given regimen is complied to. Awareness is useful for designing interventions that may help patients and caretakers adhere to prescribed treatments.

II.1 PATIENT

Age and disruption of normal development. Concerning compliance the age of children is a significant determinant. It is important to realize that cancer treatment disrupts normal psychosocial developmental tasks during childhood. At any age various resistance and control battles can occur.
Toddlers, for instance, can refuse or spat out prescribed tablets. Desperate parents dealing with these will struggles may become tired and start to skip medications. Characteristic for children of younger ages are issues as fear of separation during hospitalisation.
Adolescents are known to be the worst compliers in the pediatric age range. In adolescents adherence with oral medication during outpatient treatment is exceptionally poor and non-compliance is estimated to occur in about 50 to 60 %. Non-adherence may contribute to the inferior outcome of adolescents with leukemia compared to children of other age groups. Adolescence is typified by critical psychosocial developmental trends, which are disturbed by the intensive and prolonged treatment required for leukemia. An adolescent normally focuses on relationships with friends, gaining autonomy from family members, body image and planning their future. Rebellious behavior and disagreement with parents and other authorities normally decreases emotional dependency. Cancer treatment abruptly interferes and complicates these typical trends. Hospitalisation separates adolescents from their peers for longer periods. Privacy is limited. Patients become increasingly dependent of their family. Medication result in loss of physical attractiveness (hair loss, skin changes and weight gain) at a time when looking good or at least normal is tremendously important. Studies showed that parents not only regard proper therapy more important than their adolescent children, but also that parents are falsely optimistic about the adherence of their teenagers. Once adolescents feel well again after achieving remission, they can easily deny they have a serious illness and “forget” their pills. There will be no instant alarming symptoms convincing them otherwise. Denial and avoidance are means of limiting dependency on parents. During childhood compliance is greater when parents are responsible for administration of medication. In adolescence confusion arises when responsibilty is transferred from parents to the teenager. Frequently it is either not clear who is responsible for the tablet taking or parents and teenagers disagree on this subject. Together with the general poor communication between teenagers and parents, this confusion and disagreement play a major role in decreased compliance. Disagreement between parents and children enhances in patients older than 11 years and decreases again after age 17. Health care providers should monitor compliance of their adolescent patients

more closely. It is essential to clarify explicitly who is responsible for the drug administration, as compliance tends to increase when parents and child agree on who is to administer the medication. When teenage patients are allowed to have more autonomy, they tend to comply better with medical regimens. A feeling of personal control concerning one's health enhances adherence. Health care providers should anticipate that disruptions of normal psychosocial developments will occur during cancer treatment and that these require special care and attention (6, 9-15).

Gender. Most studies conclude that gender of the pediatric patient is not related to adherence. Some studies however mention that female adolescents are worse compliers (10,12,16).

Race. Race can be seen as an independent prognostic factor for childhood acute lymphoblastic leukemia. Differences in survival rates can be related to how pediatric patients of different races metabolize chemotherapeutic agents, specifically MTX and 6-MP used to treat leukemia. Genetic heterogeneity results in functional polymorphisms in key enzymes that metabolize MTX and 6-MP. These genetic differences in key enzymes can explain differences in drug response and covary by race. A study, conducted in America, showed that even after adjustment for known prognostic factors, racial differences in survival of childhood ALL remain. African-American and Spanish surname children had significantly higher mortality rates than did white children (17).

Malnutrition. In childhood acute lymphoblastic leukemia there is a significant difference in survival between well nourished and undernourished children. Malnourishment is more prevalent in developing countries than in developed nations. In developing countries severe malnutrition exists in certain segments of the population, especially in children younger than 5 years old. Malnutrition is a risk factor for leukemia relapse in children from both developing countries as well as social groups with nutritional deficits in developed nations. Malnourishment influences leukemia and its treatment in several ways. Malnutrition results in a poorer resistance to disease and inferior ability to withstand the toxic consequences of chemotherapy. Undernourished children suffer more often from granulocytopenia or trombocytopenia, resulting in withdrawal or decrease of chemotherapy doses. Subsequently children with a poor nutritional status frequently not receive the cumulative dose of chemotherapy prescribed in the protocol. Malnutrition can also adversely affect drug metabolism. Equal mean doses of chemotherapy during maintenance treatment result in lower systemic exposure. Physicians treating malnourished children can fail to comply with the protocol by not raising the dose of maintenance drugs to the maximum tolerated. Undernourishment is usually caused by poverty and non-adherence with extended chemotherapeutic regimes is more common in families with a low socio-economic background (1,6,18-20).

II.2 FAMILY

Interaction between patient and parents. Adherence tends to be better when the patient and its caretakers have a good interpersonal relationship. For instance, compliance improves when parents join their child during visits and stays at the hospital (7,9,10).

Psychological attention for family as a whole. Leukemia in childhood disrupts family life tremendously. It is important to not only focus on the child, but approach the family as a whole.The manner in which family members adapt and cope with the disease and its treatment, has a big impact on the adjustment of the child. All family members experience psychological changes due to the serious illness. Right from the start the coping style and distress of parents influences the response of the child to its cancer. Parents hereby initiate the sense of optimism or hopelessness felt by the patient. For instance, a child will notice when its parent is depressed or scared and subsequently less able to offer support. Not only the patient, but all family members have to deal with the same doubts and uncertainties. Parents can become overprotective or afraid for the well-being of other family members as well. This is understandable, but not contributing. Different coping styles among family members can also enhance stress in a family. Fewer family problems facilitate better adherence. It is very important to first assess a family as a whole before psychological therapy is offered. One can then judge which family member needs assistance. This might just as well be a sibling or parent instead of the ill child. Making the family as a whole cope better, enables family members to provide emotional support to the patient and hereby improve its psychological adaptation and compliance (1,15).

Marital status. Although some studies have detected no differences, several reports indicate that compliance is better in families in which the mother is married. It is noteworthy that some mothers are officially married, yet function as “single parents” as the fathers live and work apart from their families (7,10,12).

Marital friction. Chronic illnesses in general coincide with marital stress. Parents can vary in their style of coping with the serious disease of their child. Misunderstanding of each others coping behavior can generate friction, also when there had been no marital problems before. Pre-existing marital tension tends to exacerbate. This marital friction can last even after the chemotherapeutic regimen of the child has ended (15).

Family size. Several studies have demonstrated that the smaller the number of siblings a child has, the better compliance is (6,10,12).

Communication within the family. Open communication with family members is important and helps children become better copers over the long term. The tone set during the first phase of treatment usually has a lasting effect. Only in an atmosphere of open communication in which all questions can be asked and answered, children feel safe to express their numerous fears and fantasies. Studies showed that when children can openly discuss their illness, they suffer less from depression and adjust psychologicaly better once treatment is concluded (15).

Social support. Compliance is related to the available social support. A close family bond, presence of local help, encouragement, words of hope and optimistic attitudes of others improve adherence to medical regimens. For instance, when other people remind patients to take their medication, they turn into better compliers. The adaptation of the child with cancer is tightly linked to the provided social support system of the parents. When parents experience less distress, due to received emotional support, adherence with treatment enhances (10,15).

Socio-economic status. Health of populations is affected by socio-economic circumstances. Although no social class in any society is immune from non-adherence, suboptimal compliance is more likely under socio-economically deprived conditions. Both in developed as well as in developing countries poor socio-economic status is closely related to delay in diagnosis, response to treatment and long term disease free survival. Of course the problem of poverty and malnutrition is more prevalent in developing nations. Financial and transportation problems hinder poor families to attend the clinic or adhere to the protocol. The prolonged and expensive treatment of childhood leukemia cannot be afforded. Subsequently substantially fewer children with leukemia in the developing world achieve cure or long term survival. Poor socio-economic status therefore must be seen as a poor prognostic factor in childhood leukemia. Keep in mind that when a child has leukemia, its family generally falls into a lower socio-economic class as treatment is expensive and parents are not able to keep their job or social position (4,6,7,9,14,18,20,21).

Parental educational background. The development of a nation is most significantly determined by its educational standard. Education is essential to the health of a population, as it influences income, lifestyle and coping with disease. Lower levels of parental education adversely affect seeking of medical help, adherence with therapy and subsequent cure or survival from childhood leukemia. Especially the education of the mother is important. In educated families the ability and willingness to comply with the extended chemotherapeutic regimen is higher (1,4,6).

Knowledge and understanding. With increased knowledge and understanding of both the patient as well as its parents, compliance tends to improve. When patients and parents have an abstract and realistic concept of the illness and greater insight in causality, therapeutic aims and prognosis, adherence improves. Specific knowledge about drug administration is important. These specifics include information about the exact content, amount, frequency and side-effects of chemotherapeutics. Non-compliers more often misunderstand instructions given by their physician. Patients or parents may have problems with learning or memorating their doctors' statements and advices. Stress evoked by visiting a physician exacerbates this misunderstanding of instructions. A study showed that about 50% of the provided information by a doctor is instantly forgotten. Also the nature of knowledge is important. A study on diabetes control in adolescents showed an inverse "U" relation between knowledge and compliance. Adolescents with little knowledge about their disease and treatment were poor compliers. Patients who understood the nature of their illness and how to adequately administer medication complied best. Adolescents who not only were aware of their disease and therapy, but also of the consequences and prognosis on the long run had worse adherence. Apparently knowledge that frightens or depresses is discouraging and not helpful. One should realize that greater objective knowledge of disease processes does not automatically implicate greater adherence. Emotional factors and subjective satisfaction derived from the information are also important. Immediately at diagnosis one should make a child understand what is happening and why it is happening. This will positively influence its emotional response, psychosocial adaptation and compliance with treatment (7,9,10,12,15,16).

Ethnicity and culture. Large differences in lifestyles not only exist in different world regions, but also in different segments of a country's population. Non-adherence can occur in any ethnic group, yet is greater in developing countries as well as in less

affluent immigrant communities. The attitude of different ethnic groups may be relevant to compliance. Cultural differences can, for instance, affect the speed at which people worry about or tolerate symptoms and subsequently seek medical help. Convincing certain ethnic groups of the importance of the maintenance phase of treatment, once a child is in remission and appears well again, proves to be very difficult. In some countries 25 to 45% of families fail to attend the hospital at all during maintenance treatment. Survival rates from childhood acute lymphoblastic leukemia in ethnic minority groups or developing countries are lower. Studies of ethnicity can however also reflect lower socio-economic status, lower educational background, poor nutrition, high proportion of poor prognosis disease, lower quality of health care and difficulties in communication with health-care providers. One should therefore assess these factors separately in order to disentangle their effects. Studies focusing on ethnic and cultural origin have mainly been performed in America, Great-Britain and Australia. Caucasian populations were compared with Afro-Americans, Hispanics and Asians. Children from these ethnic minority groups had poorer survival rates. The lower socio-economic and educational status, poor nutrition and communication difficulties contributed to the worse outcome. These communication problems could evolve from language barriers, status or cultural differences with the generally white physicians. To people whose native language was not English and who were not used to Western medicines, it was difficult to explain the nature of the disease, treatment and its possible complications. Poor communication led to poor parental awareness of early signs and symptoms of infection and complications of chemotherapy. In Great-Britain (22) this could have contributed to the higher incidence of deaths in remission among Asian children. Communication difficulties probably also led to poor compliance. Children from ethnic minority groups received a lower quality of health care and are at risk for psychological problems. A study performed in South-Africa (7) compared adherence with treatment in black and white families. The socio-economic and educational status of the black families was lower. Once their child appeared healthy again, black parents stated they did not consider continuation with chemotherapy necessary or clinic attendance important. They were struggling to earn a living and visiting the hospital implied not only loss of a day's wages, but paying for transportation to reach the hospital as well. Clinic records confirmed the statements of the white families that about 90% never missed an appointment. However almost 90% of black families stated they never missed a clinic appointment, yet the records could only confirm this in approximately 50%. Some of these families did not regard visiting the hospital a few weeks later as missing an appointment. Other families needed interventions from their employer or home visits by social-workers first before they attended the hospital (1,6,7,9,14,18,19,21-24).

Human error. The most frequent cited reasons for non-compliance are related to human error: forgetfulness, busy lifestyle, preoccupation, inadequate supply of drugs and no systematic schedule for taking medication (10,12).

Attitude and beliefs. Compliance appears to be more related to the personality of the parents than that of the sick child. It is remarkable that anxiety, a personality characteristic that is usually seen as a negative trait, actually is one of the strongest motivators to comply. Concerning adherence, attitudes that parents and patients have toward health and medical care are significant. Compliance in fact is more determined by beliefs of the parents or patient, than objective judgements of the illness by the

doctor. These beliefs concern, for instance, the perception of the disease, accuracy of diagnosis and effectiveness of treatment. Compliant patients are more satisfied with the provided information and medical care by the health care providers. Compliance is greater in parents and patients who believe they have some control over their health (internal locus of control), compared to those who feel health is beyond their control (external locus of control). Positive attitudes toward treatment and outcome are important. When parents and patient believe that the therapeutic regimen is effective and leukemia can be cured, adherence is greater. Non-compliers tend to focus more on side-effects of chemotherapy. Patients who are easily reassured by absence of symptoms and subsequently assume they are healthy again are poorer compliers, than those with a more realistic conception of their vulnerability to illness. Non-compliers more often use denial to cope with the stress of their illness. Particularly in adolescents, who generally believe they are invulnerable, denial of the severity of their condition can lead to non-adherence. Compliers have a better future orientation (7,9,10,12,16).

Refusal of treatment. A study of adolescents who refused cancer treatment, showed that refusers believed their illness did either not change or in fact improve due to their refusal. This belief was based on disappearance of side effects when chemotherapy was stopped. The adolescents focused on the side effects and perceived them as unbearable. Refusers were convinced that cure could be achieved without therapy. They believed that their health was beyond their or their physician's control and was determined by luck, fate or God. This strong external locus of control and religiosity lowered their feelings of anxiety. It was remarkable that their mothers used similar attitudes and beliefs. Health-care providers dealing with refusers should never try to induce fear by using "scare-interventions", as these have adverse defensive effects and strengthen the refusal (15).

Uncertain outcome. Uncertainty concerning the outcome of treatment can create major stress in the lives of parents and children with leukemia. Anxiety and preoccupation with physical functions or progress of disease can evolve from this uncertainty and is referred to as the Damocless Syndrome (after the ancient Greek myth in which Damocless sat under a sword hanging by one horsehair). People tend to respond to this uncertain outcome in three manners. 1) Preoccupation with fatal return of cancer. 2) False belief that previous chemotherapy prevents tumor relapse. 3) Mental state in which one does not worry about the uncertain outcome. The first manner coincides with anxiety and other psychological problems. The second and third group use denial to cope with uncertainty. The latter group of people cope well (15).

II.3 DISEASE

Severity of illness. The naive assumption that when an illness is severe or life-threatening adherence automatically will be good is no longer tenable. More severe disease does not necessarily produce better compliance (9,10,14,16,25).

Absence of symptoms. Childhood acute lymphoblastic leukemia requires a complex treatment during an extended period of time. Once in remission, the disease is generally asymptomatic and patients feel healthy again. When doses of drugs are

missed, this will not immediately cause the symptoms of the disease to return. Now that the symptoms have cleared patients and their parents can easily forget to take the prescribed medicines or deny there is a problem. Poor drug adherence may be expected. Compliers have a more abstract concept of subclinical disease and therefore understand why continuation of therapy is also necessary when they are relatively asymptomatic. As a consequence, compliers have less difficulties with treatment of asymptomatic disease. In contrast, non-compliers maintain a more direct association between absence of symptoms and absence of leukemia, minimizing the significance of subclinical disease (9,10,13,16).

Stage of disease at diagnosis. Both in developed and developing countries people with a lower socio-economic or educational background tend to enter treatment with a more advanced stage of cancer. However, poverty and low educational standards are of course more prevalent in developing nations. Low income and less insight in health related issues may cause patients' and parents' delayal in seeking medical help. In developing nations, medical doctor awareness and knowledge of childhood cancer is often insufficient and results in delayed diagnosis and referral to centers specialized in pediatric oncology. By the time the family finally reaches a specialized center, their children suffer from far advanced leukemia. Thus at presentation more children are in the high risk category. The poorer prognosis and higher treatment costs associated with high risk leukemia might discourage both parents and physicians and thereby decrease their compliance and subsequent survival (1,2,4).

Morbidity. In different world regions, different biology of the disease itself and different environmental circumstances may result in different responses and toxicities to treatment. Morbidity is known to be higher in children with leukemia in developing nations. Developing countries are confronted with malnutrition and high prevalence of infectious diseases. As a result pediatric patients with leukemia are more vulnerable and less tolerant of chemotherapy. Low standards of hygiene, poor sanitation and poor blood transfusion practice increase the risk of infection in neutropenic patients. Due to the poor hygienic conditions antimicrobial resistance is generally high in people from developing countries. Sepsis seen in childhood leukemia in developing countries may consequently have a higher morbidity (1,2,4).

II.4 TREATMENT

Physical characteristics of medication. Adherence with medication is influenced by its appearance, color and taste. Compliance tends to improve when medication is in tablet form rather than liquid. Also the size of the tablets matters. How larger the tablet, the more difficult to swallow, the more associated adverse sentiments, and subsequently the lower the compliance (10).

Complexity of medication regimen. When drug regimen are more complex, compliance decreases. Compliance tends to improve with smaller numbers of medicines, fewer doses and less frequent administrations per day. Thus drugs will be taken more reliably when they are prescribed once or twice a day instead of more frequently. Compliance enhances when no other treatments are recommended (7,9,10,13,16).

Mode of medication administration. Compliance tends to improve when drugs are administered by the health care provider and not by the patient or parents themselves (10).

Availability of medication. In developing countries chemotherapy and antibiotics are in short supply or not available at all. Consequently treatment is often more based on which medicines are available rather than the optimal drug combination (1,4).

Duration of treatment. Time on treatment is important. When therapy requires a prolonged time, adherence seems to reduce over time (6,9,10,12,14,16).

Inpatient versus outpatient care. When compared, more patients tend to default on outpatient care than during care in a clinic (6).

Frequency of hospital visits. Adherence to medical regimens is enhanced with a greater frequency and duration of visits to the physician or hospital. It also seems that compliance with treatment is improved when the clinic attendance occured more recently or on a more frequent basis (9,10).

Therapeutic versus preventive treatment. Preventive medical regimens have lower adherence rates than therapeutic treatments. This can be explained by the following. Preventive therapy gives no relief of symptoms and thereby lacks the reinforcement a therapeutic regimen gives (11).

Effectiveness of therapeutic treatment. Compliance with therapy increases when patients and their parents can notice its effects. Thus when symptoms decrease or disappear, motivation to adhere with treatment grows stronger. In contrast, when treatment shows no apparent effects, patients and parents tend to doubt its usefulness and compliance may decrease (10).

Costs. In general treatment for chronic illnesses involves extra finances. Costs must be made to pay for hospitalization, drugs, transportation to the hospital, care for siblings left at home, loss of day's wages during visits or stays at the clinic. Financial debts may result and can persist long after conclusion of the treatment (10,15).

Painful medical procedures. Considerable progress has been achieved in reducing children's distress during painful medical procedures. During treatment of childhood leukemia bone marrow aspirations and lumbar punctures take place on a regular basis. Packages of stress, anxiety and pain management techniques, that contain medical, psychological and pharmalogical approaches, should be offered. Which approach works, varies per person. When the whole package is presented, patients can chose the option that ameliorates distress best for them (15).

Side-effects. Studies show conflicting results regarding the correlation of adherence and side effects of medication. Compliance to treatment is generally believed to be better in patients with fewer side-effects, less severe side-effects and in patients who expected their side effects to be worse or about the same as what actually happened. Non-compliers tend to accept or tolerate side-effects and restrictions due to medication less. However some studies report no correlation between compliance and

the occurrence of side-effects. One study stated that only 5-10% of patients mentioned side-effects as the reason for non-adherence (9,10,12,16,25).

Anticipatory side-effects. Nausea and vomiting are the most frequent side effects of chemotherapy and can decrease compliance. Relaxation techniques and other behavioral interventions can reduce these side-effects. More troubling, however, is conditioned reflex vomiting or anticipatory vomiting. This can occur when patients associate nausea with the physician, hospital or date of clinic appointment. Some of its symptoms occur in about 25% of patients as early as the fourth session of chemotherapy. Behavioral techniques, such as systematic desensitization, can be effective (15).

Side-effects and ethnicity or culture. In a South-African study (7) compliance determinants were assessed in black and white families of leukemic patients. The black families came from a lower socio-economic and educational background. A significantly larger number of white mothers mentioned side-effects of medication during the maintenance phase of treatment. Mainly gastro-intestinal symptoms were reported. There can be various reasons for the differences in this reported incidence of drug toxicity. White parents may have been more aware of potential side-effects and subsequently recognised and attributed them more quickly to chemotherapy. Black parents may have accepted more that a severe disease requires strong treatment and subsequently side-effects. Black parents may find it inappropriate to suggest that therapy made the child ill. Differences in reported incidence of side-effects between white and black families may also be based on adherence differences. White children showed more frequently lymphopenia during the maintenance part of treatment. This can imply either poor compliance with chemotherapy by black patients and parents or differences in drug metabolism (7).

Limited resources in developing countries. In the Western world huge progress in treatment and survival rates of childhood acute lymphoblastic leukemia has been made in the past decades. Most children, however, live in developing countries where survival rates of childhood leukemia improved only slightly. In the developing world only few children have access to optimal treatment in centers specialized in pediatric oncology. Most children with leukemia subsequently still die here. There are several reasons for this. Because clinics with required pediatric oncology expertise are scarce, their access is limited for less affluent families. Poor parents often cannot even pay the transportation to reach the hospital, let alone the extended expensive treatment. The illness is usually in a far advanced stage when patients finally reach a hospital. Diagnosis and referral to a specialized clinic is frequently delayed. Diagnostic facilities are often not adequate. Lack of properly trained medical and nursing staff results in diagnostic mistakes and deficiencies in medical care. Good microbiology, blood transfusion and radiation therapy facilities are frequently not available. Chemotherapeutic agents and antibiotics are either in short supply or not available at all. Insufficient supportive care only allows more gentle drug regimens. Limited resources in developing countries thus impair the ability to provide all its children suffering from leukemia with state-of-the-art treatment (1,2,4).

Alternative sources of treatment or support. When parents are faced with the fact that their child suffers from a serious and life threatening disease, they frequently turn to various sources of advice, cure and support. These sources can be medical,

paramedical, religious, homeopathic and unorthodox in nature. In certain cultures traditional or faith healers and religious leaders play a significant role. A study conducted in the Dr. Sardjito Hospital in Indonesia (26) showed that most parents, whose children were diagnosed with leukemia, initially resorted to both traditional folk medicine as well as to Western medicine. Examples of regularly used traditional treatments are Javanese folk medicine (dukun or ramuan jamu) or Chinese medicine. Parents viewed these forms of traditional medicine as curative. During the chemotherapeutic regimen some parents decided to solely confine to Western medicine (7,26).

II.5 HEALTH-CARE PROVIDERS

Communication between patients, parents and doctors. Prognosis of children with leukemia substantially decreases when there is poor communication between physicians, children and their parents. Direct communication improves compliance with the chemotherapeutic regimen. In order to improve adherence, the physician must meet the expectations and needs of the patient and family. Therefore the doctor should be aware of and understand the concerns parents and children have. The oncologist, for instance, should make the parents and child comprehend the diagnosis and create a climate in which all questions about the illness and medication can be asked. Poor survival rates of childhood acute lymphpoblastic leukemia in developing countries may partly be contributed to poor communication between physicians, patients and parents (6,7,9,10).

Attitude. Physicians may fail to comply with the defined chemotherapeutic protocols. A study (9) conducted in Great-Britain showed that physicians, treating childhood acute lymphoblastic leukemia, timidly prescribed oral chemotherapeutic agents before 1980. After 1980 these doctors complied more rigorously to the protocols. Subsequently not only toxicity, but also long term survival increased significantly. Strict physician adherence with prescribed dosage and timing of chemotherapy administration is known to improve survival rates in children with leukemia. Not only the physician's attitude, communication skills and interest in the patient, but also the doctor's own belief in the efficacy of treatment are important and able to increase compliance. Studies reported that patients in specialized and private hospitals comply better. The main reason is probably the enhanced and individualized attention patients and parents receive in these settings. Other investigations mention that compliers more frequently perceive their medical doctor as friendly and feel respected by the physician (9-11).

Provided information to patients and parents. Patient and parents education is crucial to ensure cooperation and compliance with the chemotherapeutic regimen. Information about the nature of the disease and the importance of adherence with treatment should be given. Clear and specific instructions about drug administration are required. Doctors are recommended to verify whether patients and parents also understood the information they provided. The knowledge and willingness of the physican to provide information play a significant role in treatment compliance. Both knowledge as well as satisfaction derived from the doctors' explanation influence adherence. The orally provided information needs to be reinforced by the use of written educational material. Education must level with the capacities of patients and

parents to absorb and comprehend. It should also address relevant local customs, lifestyles and traditional fears in order to ameliorate adherence and eradicate fears. Developing special educational materials for younger children and frequent rehearsal of important information is helpful. Parents should be taught how to openly discuss the disease and its treatment with the child. Patient education is also referred to as the single most significant determinant of the patient's psychosocial adjustment. An American study (25) examined whether strategies to improve compliance in patients with hematologic malignancies resulted in increased survival time. The educational and behavioral intervention indeed improved compliance and subsequent survival. The intervention emphasized the significance of, by example, taking medication, keeping clinic appointments, monitoring side effects, attending the clinic in case of fever and bleeding, discussing problems with health-care providers honestly, focusing on family as a whole. The exact reason why the intervention increased adherence and survival is not clear. The intervention made physicians pay more time and attention to patients and parents. The extra provided information may have improved patients' self-care and sense of responsibility and control. It subsequently may have decreased their fear and anxiety. Whatever the reason, it is obvious that survival partly depends on behavior of patients, parents and physicians and, more importantly, that this behavior can be influenced and changed (1,9,10,12,15,25).

Vocabulary. Physicians tend to use terms that are frequently not understood by patients and parents. It is remarkable that physicians are aware of the fact that they sometimes use terminology of which they themselves believe parents and children do not understand. Patients and parents subsequently have difficulties with understanding and interpreting provided information. Studies even showed considerable differences in interpretation of instructions on prescriptions (10).

Continuity of pediatric oncologist. Adherence improves when patients and parents are provided with a consistent care giver. Thus the frequency and regularity with which patients see the same primary oncologist during their outpatient visits to the hospital is important (16).

Corruption. Corruption is proclaimed to be one of the main problems in developing countries. Corruption in hospitals can decrease compliance of patients. Not only because patients cannot pay bribes or do not receive donations and are therefore forced to withhold further treatment. But also because corruption creates distrust and dislike of health-care providers, what can decrease adherence of patients. Aside from this, corruption in hospitals decreases compliance of health-care providers too. Corruption may demotivate honest and committed health-care professionals. Their frustration, demoralization or departure can affect good patient care. It may subsequently decrease adherence of both themselves as well as of their patients (5,27-31).

Development funds. A professional organisation and responsible attitude is required. For any foundation that supports health care projects in developing nations, awareness of local culture and customs is important. As stated above, corruption is often referred to as the main problem of developing countries. Ignorance or underestimation of this phenomenon is harmful. Clear rules about who should receive the donations are required. These rules should be made public to health-care providers at all levels and to patients and their families. Transparency is important. Measures to check whether

donations actually reach those intended should be taken on a regular basis by independent investigators. In this context trust is important, but not sufficient. Never be reassured by statements of supervisors alone, one should verify at the bottom. Parents and patients should be asked in a private setting by independent interviewers whether they received the donations. Confidentiality of provided information should be guaranteed in order to receive honest answers. Corruption involves secrecy and parents can be afraid that their replies harm the treatment of their children. Therefore it must be clear to all parties involved that at different levels rightful use of donations will be checked and abuse will not be tolerated. In this way more openness about the major problem of corruption is created and regular checks will not be regarded as personal insults or attacks, but as a realistic and responsible approach to limit the rampant abuse of development funds (5,27-31).

Private versus state or charity hospitals. In most developed and developing countries the availability of medical care differs significantly to various segments of the population. Excellent private clinics offer optimal treatment to affluent members of society. Various studies have reported that both survival rates as well as adherence are better in patients admitted to private hospitals. For example, a study (4) conducted in America compared survival rates of white children with acute lymphoblastic leukemia treated in private hospitals to those of white children treated in charity hospitals. The children admitted to private hospitals had significant better survival rates (1,4,16,18).

Awareness and knowledge in developing countries. Medical doctor awareness and knowledge of childhood cancer is frequently not sufficient in developing countries. Diagnosis and referral to centers specialized in pediatric oncology are therefore commonly delayed. The amount of qualified physicians and nurses are too small for the large numbers of patients. Their training needs improvement and the used facilities are often not adequate (1,2,4).

Psychological care. Profound progress in childhood cancer treatment shifted attention from palliation and terminal care to psychological care of pediatric patients and their families. This psychological care focuses, for instance, on pain and anxiety control, treatment adherence, depressive reactions and family problems. Childhood cancer requires a multidisciplinary approach and psychological care has become more important. Psychological and social preventative interventions during the diagnostic and acute phase of therapy facilitate a good psychological adaptation of the patient. The emotional tone set and response to the first treatment phases determine subsequent coping behavior throughout the whole chemotherapeutic period. Patient education makes the child understand what is happening. This has a tremendous impact on patient adaptation. Psychological care of parents and other family members is very important and enables them to provide emotional support to the patient. Social supports available to parents and lower parental distress levels tend to ameliorate the adjustment of the child. Right from the start open communication should be made possible with the children. Patients can learn to express their fears and worries about changes in physical appearance, reactions of peers, side effects of drugs and painful medical procedures. This decreases anxiety and enhances a feeling of control. This psychological care helps the child to return and function effectively at school and regain a lifestyle as normal as possible (15).

Parent organisation. Parent organisations are important and can provide psychosocial support and solidarity to children with leukemia and their families. However, strong parent organisations are not easy to establish. Tensions and conflicts can arise between parent organisations, medical professionals and organized cancer societies. Of course all members want the best care for their patients, yet their goals, roles, approaches and status differ profoundly. These problems occur all over the world, but are more severe in developing countries. Here scarcity exists of resources, parental time and energy. Cultural and hierarchical conflicts arise. Serious status differences between physicians and lay people hinder the functioning of parent organisations. Therefore organising styles must be adjusted to local cultures and needs. Leaders from parent organisations should receive training and learn and cooperate with other parent support groups. Medical doctors should be taught that strong parent organisations are beneficiary to the care of children with cancer. Physicians therefore should promote installation of parent organisations. All parties involved must understand that, once strong parent leaders operate and disagreements occur, this eventually will contribute to optimal patient care (8).

If you treat a disease
you win or lose

If you treat a patient
you win
no matter what the outcome is

III. ACUTE LYMPHOBLASTIC LEUKEMIA

The leukemias are a group of hematologic disorders characterized by the malignant accumulation of abnormal white blood cells in the bone marrow. Leukemias represent 30-35% of all childhood malignancies (32,33)

III.1 CLASSIFICATION OF LEUKEMIA

Leukemias can be classified into **acute and chronic leukemias**. In childhood 95% of the leukemias concerns acute leukemias. These acute leukemias are rapidly fatal if left untreated. In acute leukemias increased proliferation of precursor cells leads to a production of immature, not well differentiated blasts which quickly replace the normal hematopoietic elements of the bone marrow. The resulting neutropenia and thrombocytopenia can cause death through infection or hemorrhage. In contrast, in chronic leukemias there is increased proliferation of progenitor cells, but the differentiation into mature cells is maintained. Chronic leukemias are more indolent diseases which do not require immediate treatment. Chronic leukemias are rare in childhood (33,34).

Leukemias can also be classified according to the celline in which the proliferation of cells occurs. The proliferative defect can occur in the **lymphoid or myeloid** lineage, resulting in acute lymphoblastic leukemia (ALL) or acute myeloid leukemia (AML) respectively. Eighty percent of all childhood acute leukemias concern ALL (33,34).

Thus in ALL there is accumulation of lymphoid precursor cells or blast cells in the bone marrow. Both proliferation and differentiation of the blast cells are disturbed, making it impossible to mature into normal cells. The percentage of blasts in the bone marrow has to be at least 25 percent. These malignant cells expand at the expense of normal hematopoiesis. Usually the blasts also disseminate in the peripheral blood. Other sites can be invaded too, such as lymph nodes and the central nervous system (32,33).

With lightmicroscopy ALL can be **morphologically** classified according to the criteria of a group of French, American and British hematologists, the so called FAB group. Based on morphological characteristics of the malignant cells in bone marrow and blood, this FAB classification distinguishes three variants: L1, L2 and L3. Patients with FAB L3 morphology form a minor group of childhood ALL (1-3%). They most often have the mature B-cell phenotype, are very aggressive and should be treated with a special design protocol and are therefore excluded from our study (32-34).

ALL can also be **immunologically** categorized. With immunophenotyping it is possible to recognise the stage of differentiation of the lymphoblasts. Staining with immunofluorescent antibodies against several surface antigens distinguishes four variants: common-ALL, precursor-B-ALL, T-ALL and B-ALL. Immunophenotyping (which is more specific, precise and less subjective) has become more important than the FAB-classification, which is not widely used for categorization anymore. However, FAB is still useful to distinguish the L3 category (32-35).

III.2 TREATMENT REGIMENS

Essentially all antineoplastic drugs result in initiation of apoptosis, causing damage to the malignant cells that cannot be repaired. Since different cytotoxic drugs all have their own action mechanism they functionally add to each other when used in combination. Most antineoplastic regimens consist of multiple agents (36,37).

These multiple agent therapies consist of several phases. A relatively brief **induction** phase, followed by a **consolidation** phase and then prolonged **maintenance** phase. Some protocols have introduced an additional **reinduction** phase after consolidation. The purpose of the induction phase is rapid accomplishment of complete remission and restoration of normal hematopoiesis. After this phase the patient should be in complete remission. The aim of the consolidation and reinduction phase is further eradication of remaining leukemic cells. During maintenance treatment suppression of recurrence of present yet by present microscopy undetectable malignant cells is strived for. Long-term maintenance treatment has been found to reduce the risk of relapse. It is important to prevent relapse of disease because relapses are more difficult to treat and second remissions, if obtained, are usually of shorter duration (32,33,38).

III.3 EVALUATION OF TREATMENT

Complete remission during treatment is reached when less than 5% leukemic blasts are present in the bone marrow and leukemic cells are absent in peripheral blood, cerebrospinal fluid or elsewhere in the body (32,38).

Incomplete or partial remission occurs when 5 to 20% blasts are present in the bone marrow (32).

Relapse of ALL occurs when more than 20% blasts are found in the bone marrow, and/or leukemic blasts are present in peripheral blood, cerebrospinal fluid or elsewhere in the body (32).

Compliance or adherence is the extent to which a patient's behavior coincides with medical or health recommendations given by health-care providers. Compliance to medication is determined by the patient's perception of the risk compared to the benefits of the medication. Non-compliance is not restricted to patients and parents, but can also concern health-care providers (39-41).

Non-compliance of patients ranges from sporadic lapses to total withdrawal. "Refusal of treatment" is defined as rejection of any therapeutic intervention. "Abandonment of treatment" is used if therapy was initiated but not completed. "Lost to follow-up" is used if treatment was completed, but subsequent appointments were missed. To these terms can be added "drop-out" which is the same as "treatment abandonment" if it occurs during treatment. Refusal and abandonment are widespread in developing countries. The rate of childhood leukemia treatment refusal or abandonment varies from 16-50%. Treatment refusal or abandonment is recognized as the main reason of treatment failure in developing countries. Treatment refusal and abandonment are almost unknown in developed countries (42-44).

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True wealth is who you are
not what you have

Chapter 1

Influence of Socioeconomic Status on Childhood Acute Lymphoblastic Leukemia Treatment in Indonesia

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ABSTRACT

OBJECTIVE. A major reason for poor survival of childhood acute lymphoblastic leukemia in developing countries is treatment refusal or abandonment. This can be associated with parental socioeconomic status and attitudes of health care providers. Our study examined the influence of 2 socioeconomic status determinants, parental income and education, on treatment in an Indonesian academic hospital.

METHODS. Medical charts of 164 patients who received a diagnosis of acute lymphoblastic leukemia between 1997 and 2002 were abstracted retrospectively. Data on treatment results and parental financial and educational background were collected. Open interviews were conducted with parents and health care providers.

RESULTS. Of all patients, 35% refused or abandoned treatment, 23% experienced treatment-related death, 22% had progressive or relapsed leukemia, and 20% had an overall event-free survival. Treatment results differed significantly between patients with different socioeconomic status; 47% of poor and 2% of prosperous patients refused or abandoned treatment. Although poor and prosperous patients used the same protocol, the provided treatment differed. Poor patients received less individualized attention from oncologists and less structured parental education. Strong social hierarchical structures hindered communication with doctors, resulting in a lack of parental understanding of the necessity to continue treatment. Most poor patients could not afford treatment. Access to donated chemotherapy also was inadequate. Treatment refusal or abandonment frequently resulted. There was no follow-up system to detect and contact dropouts. Health care providers were not fully aware that their own attitude and communication skills were important for ensuring compliance of patients and parents.

CONCLUSIONS. Children's survival of acute lymphoblastic leukemia in developing countries could improve if problems that are associated with parental financial and educational background and medical teams' attitudes to treatment and follow-up could be addressed better.

Key Words
childhood acute lymphoblastic leukemia, compliance, socioeconomic status, developing country

Abbreviations
ALL—acute lymphoblastic leukemia
SES—socioeconomic status
COM-ALL-92—Comprehensive Protocol- Acute Lymphoblastic Leukemia-92
WK-ALL-99—Wijaya Kusuma-Acute Lymphoblastic Leukemia-99

THE SURVIVAL RATE of childhood acute lymphoblastic leukemia (ALL), the most common cancer in children, is as high as 80% in developed countries but frequently is <35% in developing nations. This difference is believed to be attributable primarily to refusal or abandonment of treatment, both of which are almost unknown in developed countries.[1-5]

Pediatric oncology units in developing countries face specific problems that should be accounted for. The main problems are a consequence of poverty and low educational standards. Lack of parental education and little awareness of health issues delay the seeking of medical help. In addition, limited knowledge and subsequent late recognition by health care providers in rural areas may delay referral to specialized centers. Consequently, children have a more advanced stage of cancer at diagnosis. The number of specialized centers is limited. Facilities often are not adequate, and training of health care providers needs improvement.

Childhood ALL is treated according to protocols. During the first phase of treatment, patients have to achieve complete remission. Subsequently, patients with ALL usually are in relatively good health and receive extensive outpatient treatment during 2 years. As with other chronic diseases, such as asthma, tuberculosis, and diabetes, noncompliance with prolonged treatment schedules is a problem. This noncompliance ranges from sporadic lapses to refusal or total abandonment of treatment. It is noteworthy that adherence failure is not restricted to patients and parents but also can involve physicians.

It is not suitable or possible simply to transfer and implement chemotherapy protocols from developed countries to developing nations. Of course, the aim is to provide adequate treatment that is able to produce equivalent results. However, intensive chemotherapy requires excellent supportive care, which often is not available. Malnutrition and high prevalence of infectious diseases increase the vulnerability of these children and make them less tolerant of chemotherapy. In addition, intensive and possibly dangerous treatment schedules should be avoided as much as possible. Both patients and physicians are more likely to fail to comply with complex and intensive protocols. The latter also are more expensive and demand larger efforts from doctors and nurses. In developing countries, therefore, less intensive, less toxic, and less expensive protocols are required. Chemotherapeutic drugs and antibiotics sometimes are in short supply or not available. Poor parents often are unable to pay for the expensive, prolonged medical care and costly medicines. [6-17]

Refusal or abandonment of treatment can be associated with parental socioeconomic status (SES). The immense gap between the poor and the more privileged in Indonesia offers possibilities to investigate the influence of several sociocultural and economic variables on treatment outcomes. SES is known to be related to long-term disease-free survival, independent of all other prognostic factors. Two important determinants, income and education, have been identified. [6,11]

Since 1992, there has been a collaborative project between Dr Sardjito Hospital in Indonesia and Vrije University Medical Center in the Netherlands. [18] Pediatric oncologists in both academic hospitals recognize therapy refusal or abandonment as a major problem in treatment of childhood ALL in Indonesia. We conducted this combined retrospective and exploratory descriptive study to gain insight into the influence of parental SES on treatment and its results. If problems that are associated with the financial and educational background of patients can be addressed better, then survival of children with ALL in developing countries may improve.

METHODS

Setting

Indonesia has ~216 million inhabitants, ~37% (80 million) of whom are children who are younger than 15 years. A childhood leukemia incidence of 2.5 to 4.0 new cases per 100 000 children leads to an estimated 2000 to 3200 new childhood ALL cases each year. Our study was conducted in Dr Sardjito Hospital of Gadjah Mada University in Yogyakarta on the island of Java. The district of Yogyakarta covers an area with a population of 4 million citizens. Dr Sardjito Hospital is a tertiary care referral hospital, where ~30 to 40 children annually receive a diagnosis ALL. [19] The pediatric department recognizes the following 3 different classes for ALL treatment: third class, second class, and very important person ward. Children are assigned to a specific ward on the basis of the income of their parents. With increasing rank, conditions on the ward improve and number of children per hospital room decreases. Parents could, on request, receive part or all of the chemotherapeutic medication either with a discount or free of charge from a Dutch charity.

Study Design

This was a combined retrospective and exploratory descriptive study. The inclusion criteria for all children in the retrospective study were newly diagnosed ALL (French-American-British classification L1 or L2), both standard and high-risk patients, and age between 0 and 16 years at diagnosis. Abstracts were made of the medical charts of patients who received a diagnosis between January 1997 and August 2002. It is important to emphasize that all patients who received a diagnosis of ALL were included in our analysis and that patients were not selected.

Children were treated by the Comprehensive Protocol-Acute Lymphoblastic Leukemia-92 (COM-ALL-92) protocol from 1997 until 1999, by the Wijaya Kusuma-Acute Lymphoblastic Leukemia-99 (WK-ALL-99) pilot protocol from 1999 until 2000, and by the WK-ALL-2000 protocol until August 2002. [19,20] The pilot protocol was accepted in 2000 as the national protocol for Indonesia. It is endorsed by the International Society of Pediatric Oncology.

Biological features of ALL and treatment results were noted. Treatment failure was defined as refusal or abandonment of treatment, treatment-related death, and progressive or relapsed leukemia. The number of hospital appointments kept and reasons given for abandonment were noted. In Dr Sardjito Hospital, information on parental education and income is obtained routinely during each admission to the clinic. Data on parental financial and educational background also were collected.

Our classification of SES consisted of parental financial status and parental educational status. The parental financial status classified children as coming from either a poor or a more prosperous family and was based mainly on monthly income level of parents. Considering income levels during a period of 6 years, we took Indonesian inflation rates into account, using the Consumer Price Index as determined by the International Monetary Fund. [21] The threshold of monthly income for poor versus prosperous families in the period from 1997 to 2002 was set at 300 000 Indonesian Rupiah in 1997, and 450 000, 650 000, 700 000, 750 000, and 800 000 Indonesian Rupiah for the consecutive years thereafter. During this period, the threshold for poor versus prosperous families was a monthly income of ~$80 US on average. We used the assigned hospital class at diagnosis only when no other unambiguous data were available. Poor patients were assigned to second- or third-

class wards and prosperous patients were assigned to the VIP ward at diagnosis. Most Indonesians have no health insurance at all.

Children were classified as coming from families with low, intermediate, or high parental education. The parent with the highest educational level determined the designated level. Families with low parental education consisted of families with parents with no education or with elementary school and junior high school education. Families who were defined as having intermediate parental education had parents with senior high school or vocational training. Families with high parental education consisted of families with a parent who was educated in an academy or a university.

We do acknowledge that there is a correlation between level of parental income and education. However, after the onset of the economic crisis in Asia in August 1997, many well-educated people became unemployed or were forced to work in fields other than those for which they were trained. Assessing parental and financial status separately, we were able to gain insight into the independent role of both determinants on treatment outcome.

On the basis of preliminary results of our retrospective investigation, we performed an exploratory descriptive study. Open interviews were held with parents, members of the parents' organization, pediatric oncologists, residents, nurses, and laboratory personnel. The respondents were interviewed intermittently both inside and outside the clinic during a period of 6 months. Data concerning the status of parental education, communication between doctors and parents, and access to donated chemotherapy were collected.

Data Analysis

The relationship between treatment results and parental financial or educational status was evaluated by the chi-squared test. The probability of event-free survival was estimated by the method of Kaplan and Meier; estimates were compared using the log-rank test. Event-free survival was measured from the date when the patient received a diagnosis of leukemia to the first treatment failure (refusal or abandonment of treatment, treatment-related death, or progressive or relapsed leukemia) or the date of last follow-up.

RESULTS

From January 1997 to August 2002, 164 patients received a diagnosis of ALL in Dr Sardjito Hospital and met the study's inclusion criteria. These 164 patients consisted of 94 (57%) boys and 70 (43%) girls. Ages ranged between 0 and 15 years. Similar to other studies, an incidence peak was observed between the ages of 2 and 4 years.

Of all 164 patients, 21 did not start therapy (18 refused treatment, and 3 died before treatment could begin). In total, 143 patients began therapy; 36 (25%) followed the COM-ALL-92 protocol, 26 (18%) followed the WK-ALL-99 pilot protocol, and 81 (57%) followed the WK-ALL-2000 protocol.

Refusal or abandonment of therapy was the most common cause of treatment failure (Fig 1). Of 164 patients, 57 (35%) refused or abandoned treatment. The distribution of refusal or abandonment per phase of treatment is as follows: 18 (32%) before start of treatment, 25 (44%) during induction, 8 (14%) during consolidation, 2 (4%) during reinduction, and 4 (7%) during maintenance treatment. Reasons given for refusal or abandonment were in 53 (93%) cases financial difficulties, in 1 (2%) case adverse effects, in 1 (2%) case fear of treatment and preference for traditional medicine, in 1 (2%) case a family problem, and in 1 (2%) case unknown. It is noteworthy that our

investigation of reasons for refusal or abandonment was not based on interviews with the families concerned; the information was obtained from medical charts and team members.

The second most common cause of treatment failure was treatment-related death. In total, 38 (23%) patients died of a treatment-related cause: infection (25), hemorrhage (6), and other causes (7). The least common cause of treatment failure was progressive or relapsed leukemia, which occurred in 36 (22%) children: progressive disease (5) and relapse (31). In summary, we found that of all patients, 35% refused or abandoned treatment, 23% had treatment-related death, 22% had progressive or relapsed disease, and 20% had an event-free survival (Fig 1).

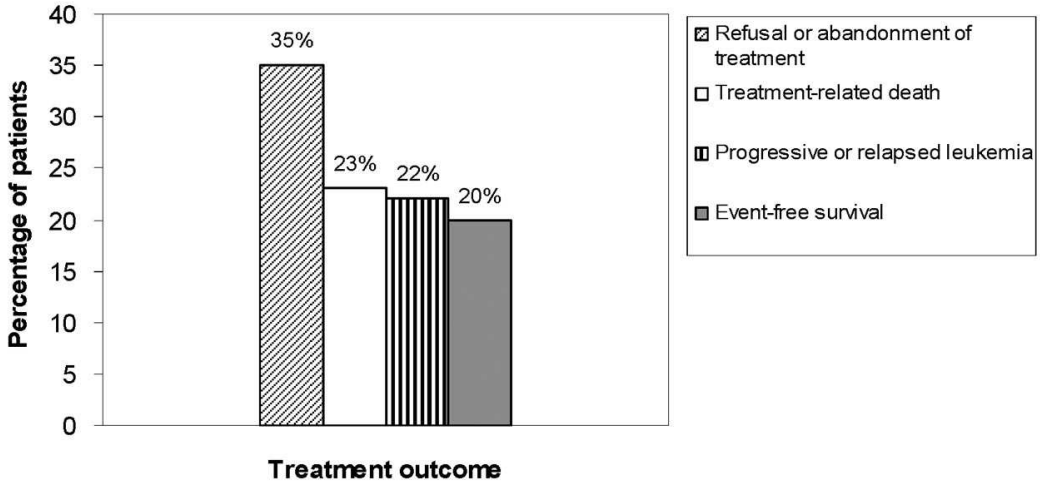

FIGURE 1
Treatment outcome in children with ALL (*n*=164).

Of 164 patients with ALL, 120 (73%) came from a poor family, and 44 (27%) were from a more prosperous one. The most likely treatment outcome in poor patients (*n*= 120) was refusal or abandonment of therapy (*n*=56; 47%), whereas in prosperous patients (*n* = 44), it was event-free survival (*n*= 20; 45%). Figure 2 shows the outcome of treatment in poor and prosperous patients. The differences in treatment outcome (refusal or abandonment, treatment-related death, progressive or relapsed leukemia, and event-free survival) between poor and prosperous patients were significant (*P* =.000). Figure 3 shows that the event-free survival estimate was significantly higher in prosperous patients than in poor patients (*P* = .000). Note that Fig 2 shows actual percentages, whereas the Kaplan-Meier estimates in Fig 3 show time-dependent probability estimates.

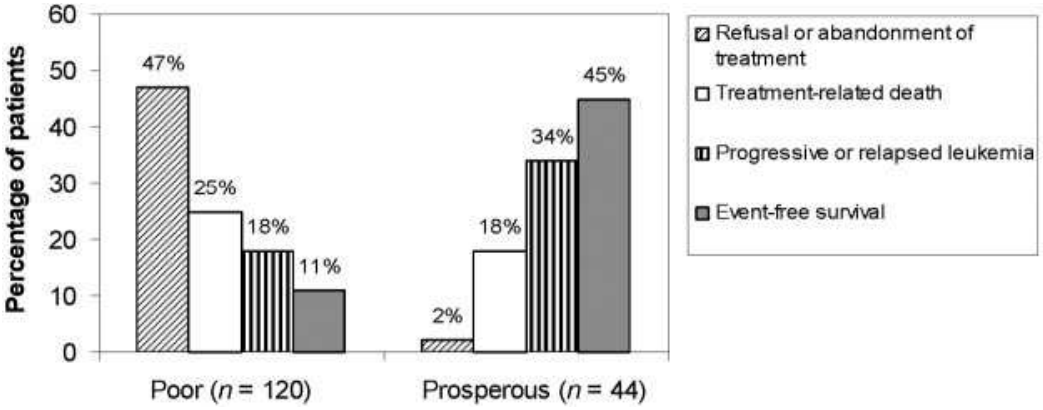

FIGURE 2
Treatment outcome per parental financial status in children with ALL (n=164; P=.000).

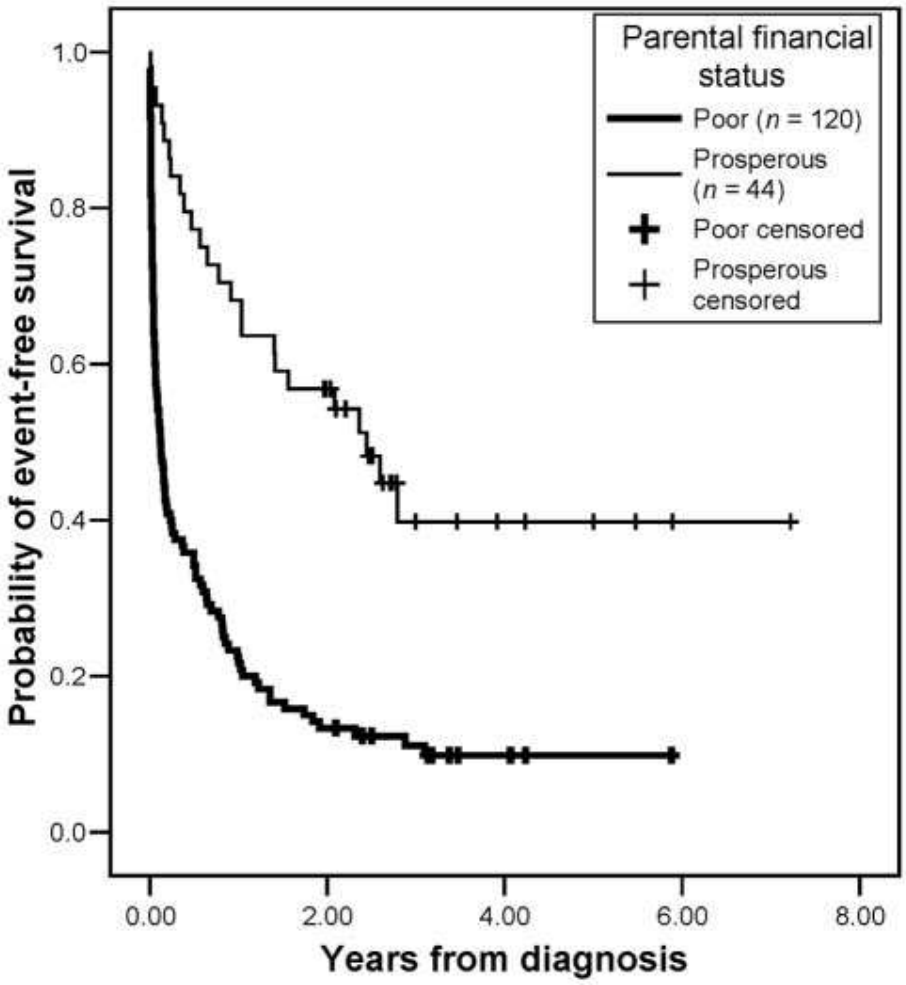

FIGURE 3
Kaplan-Meier estimates of event-free survival per parental financial status (P = .000). Events included refusal or abandonment of treatment, treatment-related death, and progressive or relapsed leukemia. Heavy solid line, poor (n=120); solid line, prosperous (n=44); heavy plus, poor censored; plus, prosperous censored.

Of 164 patients with ALL, 61 (37%) had parents with a low educational level, 66 (40%) had parents with an intermediate educational level, and 31 (19%) had parents with a high educational level. No data were available for 6 (4%) children. Figure 4 illustrates treatment results in patients with low, intermediate, and high parental education. The differences in treatment outcome between patients with different parental educational levels were significant (P = .002). Figure 5 shows that the event-free survival estimates differed significantly between patients with high, intermediate, or low parental education (P= .001). It is noteworthy that 97% of patients with low parental education, 73% of patients with intermediate parental education, and 26% of patients with high parental education were poor.

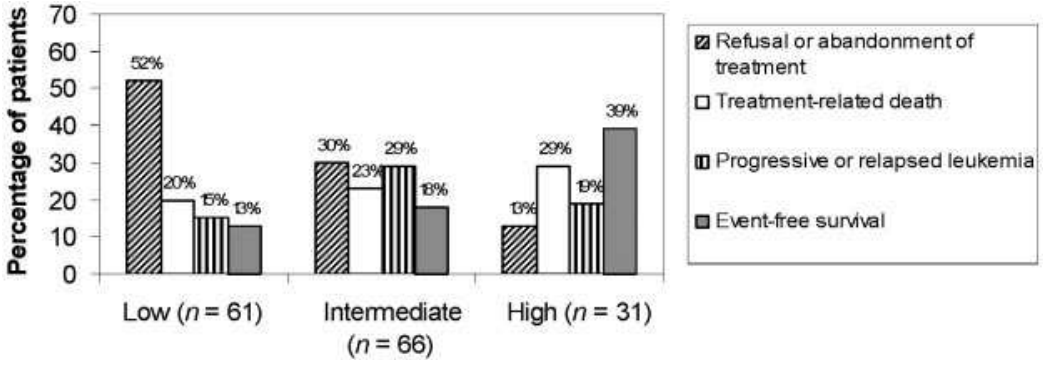

FIGURE 4
Treatment outcome per parental educational status in children with ALL (n = 158; P= .002).

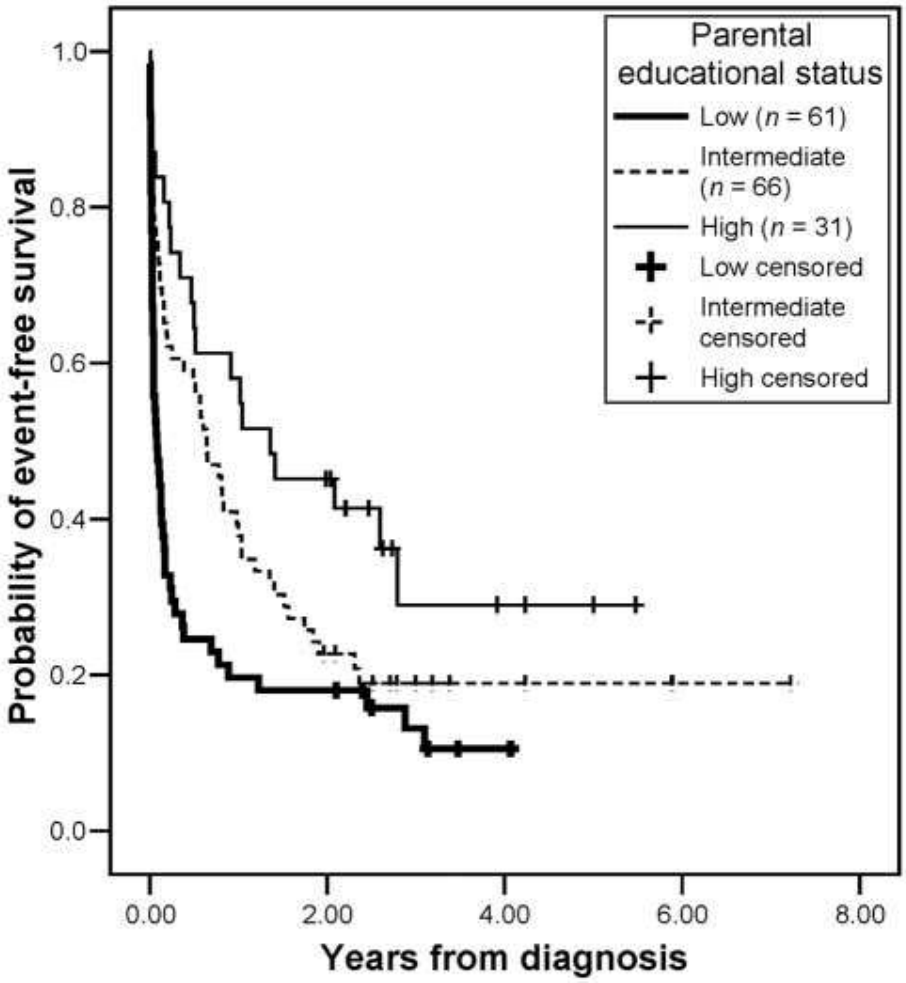

FIGURE 5
Kaplan-Meier estimates of event-free survival per parental educational status (*P*=.001). Events included refusal or abandonment of treatment, treatment-related death, and progressive or relapsed leukemia. Heavy solid line, low parental education (*n* = 61); dashed line, intermediate parental education (*n*=66); solid line, high parental education (*n*=31); heavy plus, low parental education censored; dashed plus, intermediate parental education censored; plus, high parental education censored.

To gain more insight into the reasons for the disproportionate amount of refusal or abandonment of therapy in poor and less well-educated patients, we conducted interviews with 21 health care providers and 17 parents. We found that despite that both poor and prosperous patients were treated according to the same protocol, the actual implementation of the treatment differed markedly. The pediatric oncologists faced large numbers of patients, and their time was limited. There was a disparity in time and attention provided by the oncologists for poor as opposed to prosperous patients. Only prosperous patients had the same personal oncologist during the whole course of treatment. This oncologist took personal care of prosperous patients during hospitalization, as well as during their visits to the special VIP policlinic. Most patients, however, were treated in the second- or third-class wards and the general policlinic, where they were treated by various residents. Poor patients therefore were deprived of the enhanced and individualized attention that prosperous patients and parents received from oncologists. Structured parental education about leukemia and its treatment and information about the availability of external funding was lacking for poor patients and their parents. Residents provided the parental education. However, residents lacked both experience in the field of pediatric oncology and knowledge about funds; consequently, the information frequently was not complete. Strong social hierarchical structures hindered communication between doctors and poor and less well-educated parents. As a result, many parents did not understand why it was very important for children to take their medication daily during the 2 years of treatment. Their children seemed healthy and experienced no immediate consequences when doses of drug were missed. Most parents could not afford the prolonged treatment costs (hospitalization costs, policlinic visits, transportation, loss of daily wages, bone marrow punctures, lumbar punctures, radiographs, blood transfusions, antibiotics, and chemotherapy). If needed, parents could receive part or all of their chemotherapeutic medication from charitable sources. Oncologists, however, had to inform parents about this possibility. In practice, not many parents were aware of this possibility. The procedure to request the donation was complex and not at all transparent. There were no clear rules about who could receive which medicines and at which discount. The access to donated chemotherapy consequently was inadequate. Not all health care providers believed it possible to cure poor patients with a complex disease, such as leukemia, which requires an expensive, prolonged treatment. Lack of finances and insufficient insight in the necessity to continue treatment frequently resulted in refusal or abandonment of treatment in these poor families. The hospital had no follow-up system to check whether patients attended their clinic appointments. When patients abandoned treatment, no action was taken to contact the dropouts and, consequently, the patients were lost.

DISCUSSION

Our study showed that refusal or abandonment of childhood ALL therapy was the main reason for treatment failure in Yogyakarta, Indonesia. The differences in dropout rates between poor and prosperous patients and between children from parents with low, intermediate, or high education were sizable and statistically significant. Reasons for refusal or abandonment of therapy need to be explored further in future studies. Outcome of childhood ALL treatment could be improved substantially by interventions that help to prevent refusal or abandonment of therapy. Because most dropouts occur during the diagnostic process and the first weeks of treatment, any effort to reduce their magnitude should be implemented when patients first enter the

clinic. This refusal and early abandonment of treatment can be expected to have a disproportionately adverse effect on survival, in comparison with abandonment in the later part of maintenance chemotherapy.

Kaplan-Meier estimates of event-free survival differed significantly between poor and prosperous patients and significantly among patients with low, intermediate, or high parental education. In our study, income seemed a more important determinant than education.

Regarding the interviews with health care providers and parents, we realize that the number of interviewees was limited and that one has to be careful not to extrapolate from qualitative research. However, we also believe that these interviews provided us with valuable insights. The interviews showed that despite that the same protocol is being used, there is a striking disparity in the way treatment is provided to poor, as opposed to prosperous, patients. Only prosperous patients and their parents had 1 oncologist as a consistent caregiver throughout the whole treatment. Consequently, prosperous families received more time and attention from oncologists. Previous reports of successful strategies to reduce rates of therapy abandonment in children with cancer in resource-poor countries did not mention the necessity of poor families' also having individualized attention from oncologists. [1,5] In developing countries, health care providers are faced with poor patients who die of relatively simple infectious diseases that require a relatively inexpensive, short therapy. Therefore, it is understandable that not all health care providers believed in the possibility of curing poor patients with a complicated disease, such as leukemia, which requires an expensive and prolonged treatment. The influence of the physician's own beliefs on the curability of leukemia in general and in the case of poor patients in particular on the treatment that actually is provided needs to be analyzed further. In underprivileged countries, doctors have limited resources and must decide, on a daily basis, how to allocate them with presumed maximum benefit. Some health care providers may believe that cancer is not curable and treatment therefore not worthwhile. [22]

Poor survival rates of childhood ALL in developing countries may be attributed partly to poor communication between physicians and parents. Structured and complete parental education by physicians was lacking, particularly among poor patients and their parents.Health care providers did not seem fully aware that their own attitude, their communication skills, their interest in the patient, knowledge, willingness to provide information, and their belief in the efficacy of treatment all were important and potentially are able to increase compliance of patients and parents. The access to donated chemotherapy was insufficient. In developing countries, it is important to verify whether donations reach those in need, by questioning not only the supervisors but also the recipients. Most poor families could not afford the extended and prolonged medical treatment. Lack of finances and insight into the necessity to complete the 2 years of treatment often resulted in refusal or abandonment of treatment. There was no follow-up system in place to ensure that patients with ALL attended their hospital appointments and to contact families in case of dropout.

On the basis of our retrospective and exploratory descriptive study, we recommend the following: (1) pediatric oncology centers in developing countries should provide not only prosperous but also poor patients with 1 oncologist as a consistent caregiver during the course of treatment; (2) it is crucial to provide complete parental education at diagnosis about leukemia, the necessity to complete treatment, and the availability of funds to prosperous, as well as poor, patients and parents; presenting an educational film and providing written information is recommended, because it gives complete information and saves time for the health care providers; (3) hospitals need a follow-

up system for detecting and contacting promptly families who miss hospital appointments. These insights probably also are valuable for treatment of other diseases in developing countries for which compliance is known to be a problem, such as asthma, tuberculosis, and diabetes. These measures most likely will have a positive influence on patient compliance and on outcome of treatment.

The Ponte di Legno Statement principle emphasizes that all children with leukemia, also in developing countries, have the right to receive treatment. [23,24] In line with this principle, we urge continuous, close monitoring of access to chemotherapy for poor patients in resource-poor nations. This well may enable more children worldwide to be cured of leukemia.

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Where you stand on an issue
depends on where you sit

Chapter 2

Attitude of Health-Care Providers Toward Childhood Leukemia Patients With Different Socio-Economic Status

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ABSTRACT.

Background. Treatment results differ significantly between poor and prosperous children with leukemia in Indonesia. The objective of this study was to determine whether parental socio-economic status influences beliefs, attitude and behavior of health-care providers treating childhood leukemia in Indonesia.

Procedure. A self-administered semi-structured questionnaire was filled in by 102 health-care providers (69 doctors, 28 nurses, 2 psychologists, 2 hematology technicians, 1 administrator).

Results. Most health-care providers (98%) asked parents about their financial situation. The decision to start treatment was influenced by parental socio-economic status (86%), motivation of parents (80%), and motivation of doctors (76%). Health-care providers stated that prosperous patients comply better with treatment (64%), doctors comply better with treatment for the prosperous (53%), most patients cannot afford to complete treatment (58%), less extensive explanations are given toward poor families (60%), and communication is impeded by differences in status (67%). When dealing with prosperous families a minority of health-care providers stated that they pay more attention (27%), work with greater accuracy (24%), take more interest (23%), and devote more time per visit (22%). Most health-care providers denied differences in the quality of medical care (93%) and the chances of cure (58%) between poor and prosperous patients.

Conclusions. Beliefs, attitude and behavior of health-care providers toward poor versus prosperous patients appeared to differ. These differences may contribute to the immense drop-out rate and slight chances of survival among poor leukemia patients in developing countries.

Keywords: Childhood acute lymphoblastic leukemia; health-care providers; compliance; socio-economic status; developing country.

INTRODUCTION

The cure rate of childhood acute lymphoblastic leukemia (ALL) is as high as 80% in developed countries, and frequently less than 35% in resource-poor nations. This difference is believed to be primarily due to treatment abandonment, an almost unknown problem in developed countries [1-8].
Treatment abandonment constitutes one end of the non-compliance spectrum, which ranges from occasional lapses to drop-out. Failure to adhere to treatment is not restricted to patients and parents, but can also concern physicians. Until now research has mainly concentrated on patients' and parents' compliance. However, strict physician adherence can also improve survival rates in children with leukemia. Health-care providers' own attitude, communication skills, interest in the patient, willingness to provide information and belief in the efficacy of treatment are all important and able to increase compliance of patients and parents. Poor childhood leukemia survival in developing countries may partly be attributed to poor communication between physicians, parents and patients [9-15].
In a previous study [16] performed in Indonesia we found that treatment results differed significantly between patients with different socio-economic status (SES), even though the children were treated in the same hospital with the same protocol. Treatment abandonment occurred in 47% of poor and 2% of prosperous patients. Event-free survival occurred in 11% of poor and 45% of prosperous patients. There was a striking disparity in the way treatment was given to poor, as opposed to prosperous patients. Poor patients received less individualized attention from oncologists. Structured, complete parental education was lacking and many poor patients were not informed by oncologists about the possibility of using chemotherapeutic drugs available through donations. We concluded that further analysis must be carried out regarding the influence of health-care providers' own beliefs about the curability of leukemia in general, -and of poor patients in particular-, on treatment given [16,17].
Circumstances in Indonesia likely reflect unreported experiences in many parts of the developing world. More than 80% of the world population live in developing countries and the majority of these people come from poor socio-economic backgrounds. Therefore the impact of parental SES on beliefs, attitude and behavior of doctors affects many children with cancer [18].
In this study we want to gain more insight into the influence of parental socio-economic status on beliefs, attitude and behavior of health-care providers treating childhood ALL in Indonesia. Is there a difference in attitude and care between patients with poor versus prosperous backgrounds? If there is a difference, it may contribute to the immense drop-out rate and poor survival among the less affluent. Survival of childhood ALL in developing countries may improve if different approaches by health-care providers are acknowledged and if possible problems associated with socio-economic backgrounds can be better addressed.

METHODS

Setting

Indonesia has about 216 million inhabitants of whom approximately 52% live on less than 2 US dollars per day. Like in other developing countries, there is an immense gap between the poor and the more privileged [19,20]. Indonesia has an estimated 2000-3200 new childhood ALL cases each year. Our study is conducted in the academic Dr

Sardjito Hospital in Yogyakarta, where annually approximately 30-40 children are diagnosed with ALL. Childhood ALL is treated according to WK-ALL-2000 protocol during 2 years [17,19,21].
The pediatric department distinguishes four classes: third, second, first, and VIP. With increasing rank, conditions on the ward improve and number of children per hospital room decreases. Two policlinic types are distinguished: general and VIP. Most patients are poor and attend second or third class wards and the general policlinic where they are treated by various junior residents, who change over to other wards every month. These residents lack experience in the field of pediatric oncology. Prosperous patients attend VIP or first class wards and the VIP policlinic where they are treated by their personal oncologist. VIP wards are operated by senior residents. There are no differences in nursing services between the various wards.

Study design

This cross-sectional study consisted of a self-administered semi-structured questionnaire and was part of a larger questionnaire and more extensive research on compliance with childhood ALL treatment in Indonesia. All health-care providers working at the pediatric hematology-oncology department were contacted individually by the researcher and requested to complete the questionnaire at home or in the hospital. The questionnaire focused on the influence of parental socio-economic status on beliefs, attitude and behavior of health-care providers treating childhood ALL. The questionnaire contained statements that health-care providers could evaluate on three or five-point rating scales. A panel of Dutch and Indonesian doctors and psychologists assured appropriate, clear and coherent statements. The questionnaire was pilot-tested for its content, for the clarity of language and for cultural sensitivities on 4 Indonesian and 4 Dutch health-care providers. A few minor adjustments were made on the basis of the pilot-test. The questionnaire was anonymous and participants were assured of the confidential nature of their answers. Participants self-identified their professional title as pediatric oncologist, resident, nurse, psychologist, hematology technician or administrator, which was the only demographic variable collected. The study was accepted by the Medical Ethics Committee of Dr Sardjito Hospital. It is noteworthy that this questionnaire study was conducted before the results of our previous medical charts study [16] were presented or published. Participants therefore had no prior knowledge of the important differences found in treatment outcome between poor and prosperous patients.

Data Analysis

Data management and analysis were performed with SPSS for Windows 12. Frequency distributions were calculated. Reliability of items in this questionnaire was established. Cronbach's alpha coefficient was calculated.

RESULTS

From November 2004 till August 2005 all 135 health-care providers (hcp) working at the pediatric hematology-oncology department were requested to participate in our study. A total of 102 providers (response rate 76%) participated and returned questionnaires (Table I). Cronbach's alpha varied between 0.70 and 0.89 (Table II).

Table I. Health-Care Providers Participating in Questionnaire Study

Health-Care Providers	N	Response Rate (%)
Pediatric Oncologists	4	100
Residents	65	78
Nurses	28	67
Psychologists	2	67
Hematology Technicians	2	100
Administrator	1	100
Total	102	76

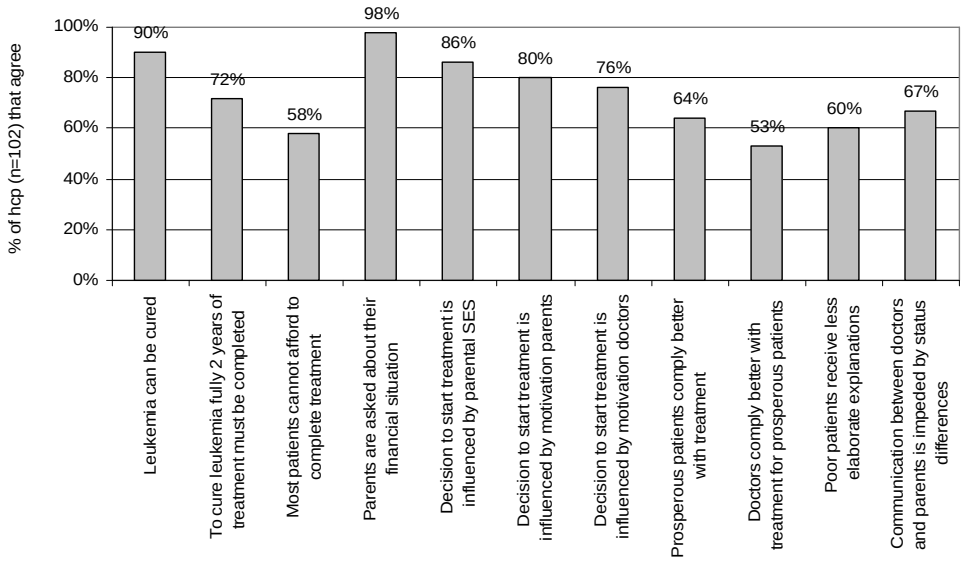
Table II. Beliefs, Attitude and Behavior Constructs of Health-Care Providers, and Internal Consistency Reliability

Beliefs, Attitude and Behavior Constructs assessed	N	Items	Cronbach's alpha
Curability of childhood ALL	92	7	0.76
Health locus of control	100	4	0.70
Necessity to complete treatment	100	5	0.76
Awareness of parental SES	101	2	0.77
Influence SES on decision to start treatment	102	3	0.72
Influence SES on attitude health-care providers	102	5	0.89
Influence SES on treatment adherence health-care providers	102	7	0.74
Influence SES on parental education	102	2	0.71
Influence SES on quality of care	86	9	0.73
Importance of parental education and communication	101	5	0.81
Openness of communication	99	6	0.73
Influence consistent oncologist on treatment compliance	90	2	0.79
Influence consistent oncologist on quality of care	99	5	0.70

Influence Parental SES on Beliefs of Curability of Childhood ALL

The state of health in children with leukemia is beyond doctors' control and is determined by luck, fate or God according to 35 hcp (34%). The state of health in children with leukemia can be influenced by health-care professionals according to 85 hcp (83%). Leukemia can be cured according to 92 hcp (90%). In order to cure leukemia fully 2 years of chemotherapy must be completed according to 73 hcp (72%). However, most patients will not be able to complete treatment due to financial problems according to 59 hcp (58%) (Figure I). There is no difference in the chances of cure between poor and prosperous patients according to most hcp (n=59, 58%). Yet a considerable number of hcp (n=40, 39%) did believe that the children of prosperous parents have an increased chance of cure compared with poor parents.

Figure I. Beliefs, Attitude and Behavior of Health-Care Providers (n=102) toward Influence of Parental SES on Childhood ALL Treatment



Influence Parental SES on Decision to Start Treatment

The decision to start or not to start treatment is influenced by the financial situation of parents according to 88 hcp (86%): sometimes (28), regularly (23), frequently (24), always (13). Almost all hcp (n=100, 98%) said that they ask parents about their financial situation and possible, financial problems: sometimes (26), regularly (26), frequently (26), always (22). Ninety-six hcp (94%) asked parents if there is a necessity for postponing or withdrawing from certain aspects of prescribed treatment due to financial problems: sometimes (33), regularly (36), frequently (11), always (16).

The decision to start or not start therapy is further influenced by the motivation of parents according to 82 hcp (80%): sometimes (43), regularly (10), frequently (19), always (10). And by the motivation of doctors according to 78 hcp (76%): sometimes (34), regularly (8), frequently (17), always (19). Prosperous parents comply better with therapy according to 65 hcp (64%). Physicians comply better with ALL treatment for prosperous patients according to 54 hcp (53%).

Influence Parental SES on Attitude of Health Care Providers

Most hcp said that they perceive no difference in respect (n=87, 85%) or empathy (n=88, 86%) toward either poor or prosperous families. When dealing with prosperous families a minority of hcp declared that they pay more attention (n=28, 27%), work with greater accuracy (n=24, 24%), take more interest (n=23, 23%), and devote more time per visit (n=22, 22%).

Influence Parental SES on Parental Education

Clear explanations to patients and parents are crucial to ensure cooperation and compliance with chemotherapeutic regimen according to 101 hcp (99%). Toward poor parents less elaborate explanations about the disease and its treatment are given according to 61 hcp (60%), and vocabulary used is simplified according to 59 hcp (58%). Sixty-eight hcp (67%) admitted using medical vocabulary with parents and patients which they knew parents and patients would not understand: sometimes (64), regularly (4).

Influence Parental SES on Communication

Poor communication between patients, parents and doctors decreases the prognosis of children with leukemia according to 88 hcp (86%). Some difficulties in openly discussing the disease with parents and patients are encountered according to 51 hcp (50%), and more severe difficulties are experienced according to 14 hcp (14%). Fifty-six hcp (55%) are uncertain if they are able to create a climate in which questions can be asked by parents and patients, and 1 hcp (1%) felt not capable of creating this climate. Communication with parents and patients, particularly toward poor families, is impeded by differences in status and social hierarchical structures according to 68 hcp (67%): sometimes (54), regularly (14).

Influence Parental SES on Quality of Medical Care

To improve compliance it is, in general, important that patients and parents should have the same personal oncologist during their 2 years of outpatient hospital visits according to 84 hcp (82%). Specified to their own hospital, 23 hcp (23%) agreed with the statement that continuity in care for poor patients at the general policlinic is insufficient because poor children are treated by residents who change over to other wards every month, in contrast to prosperous children who are treated at the VIP policlinic by the same personal oncologist. However, most hcp (n=69, 68%) disagreed with this statement. In fact most hcp (n=95, 93%) mentioned that there are no differences in the quality of medical care, time and attention between the different socio-economic classes.

DISCUSSION

This study showed that parental socio-economic status influences beliefs, attitude and behavior of health-care providers in Indonesia. There was a difference in the quality of care toward parents and patients with poor versus prosperous socio-economic backgrounds. This difference may play a role in the striking disparity of the drop-out rate (poor: 47%, prosperous: 2%) and event-free survival (poor: 11%, prosperous: 45%) between poor as against prosperous patients [16].

We found that in a developing country, where until recently most patients had no health insurance, health-care providers were very much aware of the fact that money is a prerequisite to receiving medical care. Health-care providers wanted to know in advance about the financial position in which the families involved found themselves. They did not hesitate to ask parents about their finances. The decision to start or not to start treatment was influenced by the parental socio-economic status. We also learned that many health-care providers assumed that prosperous parents were more motivated to adhere to ALL treatment than poor parents and that many health-care

providers expected doctors to comply better with the therapeutic regimen for the prosperous.

First it is important to state that we neither underestimate the burden that poverty brings, nor do we ignore that in developing countries the availability of medical care for the poor is restricted. We understand that health-care professionals have limited resources and must decide on a daily basis how to allocate them with presumed maximum benefit [22,23]. Yet we do want to emphasize that it is important for health-care providers to be aware of these perceptions as they may result in a self-fulfilling prophecy. If you expect people to perform less, your own input may decrease and subsequently the compliance of parents and patients may diminish and lesser performance and treatment results evolve.

We also learned that almost all health-care providers believed ALL is curable and most understood that the total treatment of 2 years needs to be completed. Yet at the same time many providers expected that most patients could not afford to complete treatment. Though the majority of health-care providers stated that the chance of cure is equal to all patients, still a considerable number admitted to their belief that more prosperous patients have a better chance of survival. Our previous study in Dr Sardjito Hospital found that event-free survival is indeed significantly higher in prosperous patients [16].

Almost all health-care providers mentioned that parental education is crucial, yet most declared that they give less extensive explanations to poor families. Many providers were uncertain whether they are able to create a climate in which questions can be asked by parents and patients. Most health-care providers stated that their communication is hindered by differences in status and social hierarchical structures.

The division between a VIP policlinic with oncologists for the prosperous and a general policlinic with residents changing over to other wards every month for the poor, implies that during the 2 years of outpatient care poor patients probably receive less time and attention from oncologists and thus less expertise. Yet most health-care providers denied that there is a difference in the quality of medical care between the poor and the prosperous and stated that they do not miss continuity in care at the policlinic for the poor. The awareness that individualized attention is essential for parents and patients and increases compliance and treatment outcome, needs to rise in developing countries too, because you cannot change what you do not acknowledge.

In a prior study we found that many poor families were not informed about chemotherapy available through donations [16]. Underlying reasons for limited access and for lower quality of medical care given to children from poor families in developing countries need to be further explored in future studies. We believe that lack of finances, though important, is not the sole reason.

Answers to the questionnaire may have been influenced because interviewees gave socially acceptable answers. It is important to place this tendency to give socially desirable answers in a cultural context. In Java it is considered inappropriate and disrespectful to criticize and thereby offend one of their highest moral principles: preservation of existing social harmony and hierarchical structures. Any kind of criticism, conflict or unrest should be avoided [24]. Also for the Javanese health-care providers in our questionnaire this may have implied that it is considered more appropriate and ethical to give falsely positive impressions instead of more honest critical remarks.

In developing countries the importance of health-care providers' perceptions, beliefs, attitudes and communication skills is frequently underestimated. Health-care professionals need to realize that their own expectations and subsequent behavior

differ between families with poor versus prosperous socio-economic backgrounds. This difference may play a role in the immense drop-out rate and slight chances of survival among less affluent patients. Awareness must grow that health-care providers themselves have an important influence on the compliance of parents and patients and thereby can influence treatment results and possible survival of children with ALL.

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That what is not given
is lost

Chapter 3

Does Aid Reach the Poor? Experiences of a Childhood Leukaemia Outreach-Programme

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ABSTRACT

Previously, we found that the access to donated chemotherapy for childhood leukaemia patients in Indonesia was limited: only 16% of eligible families received donations. After the introduction of a structured parental education programme, we examined the access of parents of children with leukaemia to donated chemotherapy in an Indonesian academic hospital. The programme consisted of a video-presentation in hospital, information-booklet, audiocassette, DVD, procedures for informed-consent, statement of understanding for donated chemotherapy and a complaints-mechanism. Of 72 new patients, 51 parents (71%) were interviewed by independent psychologists using questionnaires. Parents of 21 patients (29%) did not participate because their children dropped-out (n = 10) or died (n = 11) before an interview took place. Four patients had health insurance and did not need donated chemotherapy. Access to donated chemotherapy was improved: 46/47 patients (98%) received donations. Structured parental education improved the access to donated chemotherapy. Outreach-programmes may benefit from this approach. This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure.

Keywords: Childhood acute lymphoblastic leukaemia; developing country; outreach- programme; aid; parental education.

Abbreviations: ALL- acute lymphoblastic leukaemia

INTRODUCTION

The problem of transparency, defined here as assuring proper aid-assignment and distribution, is a key concern in humanitarian action in developing countries. Does aid reach the poor? The problem, however, has hardly been investigated or discussed, because participants are afraid that openness about its risks and extent may harm the public support and the ability to operate in a country. This silence, however, inhibits sharing and learning. [1,2]

Open discussion and search for solutions are required. This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure. We tried to improve aid-assignment in our childhood leukaemia outreach-programme between paediatric-oncology departments in Indonesia (Dr Sardjito Hospital, Yogyakarta) and The Netherlands (VU University Medical Centre, Amsterdam).

The cure rate of childhood acute lymphoblastic leukaemia (ALL), the most common cancer in children, is as high as 80% in the developed countries and is frequently less than 35% in the developing nations. [3-11] In a previous study, [12] we found that the treatment results in Indonesia differed significantly between 164 children with different socio-economic backgrounds, eventhough the children were treated in the same hospital with the same protocol. Treatment abandonment occurred in 47% of 120 poor and 2% of 44 prosperous patients. Event-free survival occurred in 11% of poor and 45% of prosperous patients. There was a striking disparity in the way the treatment was given to poor, as opposed to prosperous patients. Poor patients received less individualised attention from oncologists. Parental education about leukaemia, its treatment and the possibility of receiving chemotherapeutic drugs available through donations from a Dutch charity was lacking. [12]

The charity provided donations to give chemotherapy for free, but not enough to provide all patients. Health-care providers thus had to select beneficiaries. There were no clear criteria for families to receive donated chemotherapy. It was assumed that oncologists informed all families that their children could receive a part or all their chemotherapy for free if required. However, in practice only 27 patients (16%) were informed about this possibility. Most patients (n=137, 84%) were not informed at all, and had to pay for the donated chemotherapy. The charity was not aware that parents were paying for the donations. Many poor parents could not afford the expensive medicines and the treatment costs, and had to abandon treatment of their children. Ninety-five percent of the poor patients, who abandoned treatment, dropped-out because their families could not pay for treatment anymore. These results taught us that the access to parental education and donated chemotherapy for the poor had to be improved. We also learned that beneficiaries should participate in aid-implementation. Starting from January 2004, a programme was introduced in Yogyakarta to improve the access to donated chemotherapy through parental education.

MATERIALS AND METHODS

Setting

More than 80% of the world's population lives in the developing countries and the majority of these people come from poor socio-economic backgrounds. [13] Indonesia has about 218 million inhabitants. Literacy is around 92%. [14] Indonesia has an estimated 2000-3200 new childhood ALL cases annually. Our study is conducted in the academic Dr Sardjito Hospital in Yogyakarta, where approximately 30-40 children are diagnosed with ALL each year.[15] Childhood ALL is treated according to WK-ALL protocol. Total treatment takes 2 years.[16] On the basis of our findings of limited access to donations if health-care providers selected beneficiaries, [12] the Dutch charity changed its policy: from 2004, enough donations were provided to give chemotherapy for free to all patients. The paediatric department distinguishes four classes: third, second, first, and VIP. With increasing rank, ward conditions improve and the number of children per hospital room decreases. Two polyclinic types are distinguished: general and VIP. Most patients attend second- or third class wards (operated by junior residents who are daily supervised by oncologists) and general polyclinic (staffed by junior residents with no experience in the field and only supervised at their request). Patients who attend VIP- or first class wards (operated by senior residents who are daily supervised by oncologists) and VIP polyclinic (staffed by oncologists) have the same oncologist throughout the treatment.

Classification of socio-economic status

Our socio-economic status classification into poor and prosperous families was based on 2 determinants: 1) Monthly income level of parents. Threshold of monthly income for poor families versus prosperous families was set at 1,000,000 Indonesian Rupiah (about 100 US dollar). 2) Assigned hospital class during diagnostic process. Poor patients were assigned to second or third class wards, and prosperous patients were assigned to VIP or first class wards at diagnosis. Both socio-economic determinants were obtained routinely during hospital admission. In case of discordance between both determinants, assigned hospital class at diagnosis prevailed.

Parental education programme

An education programme was designed for all parents, and enabled them to participate in aid-implementation in several ways: 1) Accountability to parents was improved. Parents were informed about the donations that they were supposed to receive according to clear and simple rules. 2) Estella Fund statement of understanding was introduced. Parents were formally made aware of their right to receive the donations by signing this statement with the donating agency. 3) A complaints-mechanism was installed. Parents were given opportunities to communicate or complain about the donations with Estella Fund by mail or e-mail. Starting from January 2004, one social paediatrician was designated to provide this programme at diagnosis. This paediatrician invited parents to watch a video-presentation together and ask questions. The video-presentation ensured that poor and prosperous parents received the same information: a paediatric-oncologist explained the disease and its treatment. Parents were informed about donated chemotherapy from Estella Fund. Clear rules were explained: all childhood ALL patients were entitled to receive methotrexate, vincristine, daunorubicin and L-asparaginase for free. For 6-mercaptopurine 400 Indonesian-Rupiah (about 0.04 US dollar) was charged. Parents had to pay for dexamethasone (about 0.04 US dollar) themselves. Informed-

consent and Estella Fund statements of understanding were introduced and explained. Parents, patients, survivors and parent-organisation representatives encouraged parents to comply with treatment and not to abandon it. In addition to this video-presentation, parents received an information-booklet, audiocassette and DVD containing the same information.

Study design
A panel of Dutch and Indonesian doctors and psychologists created a structured questionnaire to be studied in a cross-sectional manner for all parents. It was tested on a group of parents for content, clarity of language, cultural sensitivities and was modified appropriately. The aim was to assess the access of poor and prosperous parents to parental education and donated chemotherapy after introduction of the programme. Participants were parents of childhood ALL patients, who were hospitalised or who visited polyclinic at Dr Sardjito Hospital between November 2004 and April 2006. All children (0-16 years) with newly diagnosed ALL were included. Respondents were interviewed by three independent psychologists. Anonymity and confidentiality were guaranteed. The study was approved of by the Medical Ethics Committee of Dr Sardjito Hospital.

Data analysis
Data management and analysis were performed with SPSS for Windows version 13. Frequency distributions were calculated. Relationships between parental socio-economic backgrounds and access to parental education and donated chemotherapy were evaluated by chi-squared test.

RESULTS

From November 2004 till April 2006, 72 childhood ALL patients attended Dr Sardjito Hospital. Parents of 51 children (71%) were interviewed. Parents of 21 patients (29%) did not participate, because their children dropped-out (n=10) or died (n=11) before an interview took place. There were no significant differences in age, gender, risk classification, parental educational background and socio-economic status between respondents (n=51) and non-respondents (n=21).

Patient Characteristics
The 51 children consisted of 32 boys (63%) and 19 girls (37%). Age at diagnosis ranged from 2 until 16 years. At the time of interview, 23 children (45%) were undergoing the first intensive part of chemotherapy (induction, consolidation, reinduction), 25 children (49%) underwent maintenance treatment and 3 children (6%) had completed treatment. According to our socio-economic status classification, 18 children (35%) came from prosperous and 33 children (65%) from poor families.

Parental education
Before analysing the parental education programme given by the social paediatrician, we wanted to gain insight into whether parents were also informed about leukaemia and its treatment by doctors working at the haematology-oncology department. At diagnosis, parents of 31 patients (61%) received explanation from these doctors about leukaemia and its treatment. Of 18 prosperous patients, parents of 17 children (94%) indicated that they received explanation from their private oncologist. Of 33 poor patients, parents of 14 children (42%) said that they received no explanation from

doctors about the disease and therapy at diagnosis. Significantly less poor than prosperous parents did receive this explanation (*P=0.006*) (Table 1).
During the parental education programme with the social paediatrician, only 13 parents (26%) received video-presentation in hospital. Reasons for not providing video-presentation to all parents were that either the social paediatrician was too busy or a television-room was not available. Parents mentioned having received information-booklet (n=48, 94%), audiocassette (n=36, 71%), and DVD (n=28, 55%). Of all parents who did receive the various materials, contents were considered informative and helpful: video-presentation in hospital (100%), information-booklet (88%), audiocassette (89%), and DVD (93%). Most parents (n=42, 82%) got an opportunity to question the social paediatrician. No significant differences existed between poor and prosperous parents in receiving various parts of the education programme (Table 1).
Informed-consent was signed by almost all parents (n=47, 92%). However, its meaning was unclear to 41 parents (87%). No significant differences existed between poor and prosperous patients in signing or understanding informed-consent (Table 1).

Table 1. Parental education for poor and prosperous patients (n=51).

Parental education	Poor (n=33)	Prosperous (n=18)	*P*
Explanation at diagnosis by doctors at haematology-oncology department	19 (58%)	17 (94%)	0.006
Parental education programme by social paediatrician:			
Video-presentation in hospital	9 (27%)	4 (22%)	ns
Information booklet	31 (94%)	17 (94%)	ns
Information audiocassette	24 (73%)	12 (67%)	ns
Information DVD	17 (52%)	11 (61%)	ns
Opportunity to question paediatrician	26 (79%)	16 (89%)	ns
Informed-consent:			
Meaning informed-consent is clear	4 (12%)	6 (33%)	ns
Signed informed-consent	30 (91%)	17 (94%)	ns

Donated chemotherapy
Four families had health-insurance and did not need donated chemotherapy. These four patients were excluded from our analysis of donated chemotherapy. At diagnosis, information about donated chemotherapy from Estella Fund was received by 41 (87%) of the 47 parents. This information was clear, according to 36 parents (77%). Estella Fund statements of understandings were signed by 38 parents (81%). Donations were received by 46/ 47 parents (98%). The reason for not letting all parents sign statements of understanding with Estella Fund was that this was forgotten. Prescribed drugs were not always available at the pharmacies according to 9 parents (19%). Most frequently recorded was 6-mercaptopurine (n=12), which was not available. Only 2 parents (4%) stated that they had contacted Estella Fund.

However, 31 parents (66%) mentioned that they would want to contact Estella Fund. Reasons for not making contact were that parents either did not know how to make contact (n=9), or considered the procedure too difficult (n=2). No significant differences existed between poor and prosperous patients in receiving information about Estella Fund, understanding its purpose, signing its statement or receiving donated chemotherapy (Table 2).

Table 2. Donated chemotherapy for poor and prosperous patients (n=47).

Donated chemotherapy	Poor (n=33)	Prosperous (n=14)	*P*
Donated chemotherapy from Estella Fund:			
Received information about Estella Fund	29 (88%)	12 (86%)	ns
Purpose Estella Fund is clear	25 (76%)	11 (79%)	ns
Signed Estella Fund statement of understanding	27 (82%)	11 (79%)	ns
Received donated chemotherapy	32 (97%)	14 (100%)	ns

DISCUSSION

This study showed that structured parental education in an Indonesian academic hospital improved access to donated chemotherapy: we assessed 71% of parents in our sample, and found that 98% of patients received donations, as opposed to 16% in the past. Poor and prosperous parents were informed about leukaemia, its treatment and chemotherapeutic drugs available through donations. No significant differences existed between poor and prosperous parents in receiving various parts of the education programme. However, it proved to be not possible to provide the video-presentation to parents individually. Because of this outcome, we changed our approach and now educate parents in small groups once a week. We also learned that extra attention must be given to informed-consent, which most parents signed, yet did not understand.

We found that doctors working at the haematology-oncology department often failed to explain diagnosis and treatment to poor families. In Indonesia children are assigned by socio-economic status to different levels of medical care. However, also poor children need an oncologist, not just a rotating junior resident, taking care of them throughout the treatment. Awareness must grow that communication with all families, poor and prosperous, is essential. Doctors themselves have an important influence on compliance of parents and patients, and hereby can influence treatment results and possible survival of children with ALL. [17-25]

We learned that not only an education programme for parents, but also an education programme for health-care providers is required. This programme should not only aim at improving knowledge and skills of doctors, but it must also raise awareness about the significant impact that interest in poor and prosperous patients can have. Willingness to provide information to all parents and patients, checking whether information has been understood and training of proper communication skills are of the utmost importance.

A limitation of this study was that parents of children who dropped-out (n=10) or died (n=11) were not interviewed. Extensive drop-out research has taken place. Families of our 10 drop-outs already participated: all declared that they did receive the parental education programme and donated chemotherapy (M.N. Sitaresmi, personal communication). This tells us that patients drop-out despite availability of an education programme and a donated chemotherapy. However, preliminary results of a large medical records study have shown that the drop-out rate among poor patients declined significantly after the introduction of the parental education programme, which informed families about the availability of donated chemotherapy (S. Mostert, personal communication).

Before the introduction of the parental education programme, health-care providers charged for the donated chemotherapy. This cannot be accepted. Aid agencies must improve the quality of their accountability to beneficiaries because if beneficiaries know what they are to receive, beneficiaries can complain if aid is not given. Criteria and procedures for assigning assistance should be clear, simple and transparent. Complexity makes it difficult for beneficiaries to call aid organisations and doctors to account because criteria cannot be comprehended and retained. Health-care providers should not select beneficiaries themselves. In 2004, the Dutch charity changed its policy and provided enough donations to give chemotherapy for free to all patients: donation-assignment no longer depended on selection procedures by health-care providers. The credibility of the criteria can be undermined where doctors do not accept the criteria. It may be felt that everyone is poor and needs assistance. Or it may be felt that it is not worthwhile to provide donated drugs to the poor because poor families cannot afford additional treatment costs and will abandon the treatment anyway. This may lead to redistribution according to local perceptions. (Insight into the extent of additional costs in the developing countries is lacking, and requires future studies) [2,11,26-28] Dutch participants initially considered it best to provide all chemotherapy for free to make rules as simple and transparent as possible. Indonesian participants considered this to be unfair towards patients with other types of cancer who do not receive donations, and mentioned that the parents might not realise the importance and value of drugs if all medicines were given for free. Also in social psychology, it is described that people attach more value to that which requires an effort or has its costs. [29,30] We decided together to donate most of the chemotherapies completely, to ask a small fee for one medicine and let parents pay for an inexpensive medicine themselves. In practice, this means that parents paid about 0.04 USD per day instead of 1 USD per day.

It is important that participants of outreach-programmes examine and understand the nature of power in indigent societies, where commonly strong social hierarchical structures exist. Vulnerability of the poor should be understood in terms of powerlessness rather than simply lacking basic means. Power and powerlessness determine access to aid. Those who lack power cannot safeguard their rights. Aid may be used by the strong to neglect, exclude or exploit the powerless. Supervision by aid agencies should therefore be improved. Monitoring and reporting are critical tools for accountability, but can also be used to conceal evidence of inappropriate use of donations. The extent to which reporting processes can be checked is restricted. Access may be limited, and agencies may make only occasional visits. The same personnel is frequently responsible for both implementing and monitoring a project. This makes it almost impossible to track improper use of donations. Also after installation of complaints-mechanisms, the extent to which beneficiaries are truly independent and able to complain without fear of losing aid is limited. [2,11,26-28]

On the basis of our study and in line with Ponte di Legno Statement (emphasising that all children with leukaemia, also in the developing countries, have the right to receive treatment),[31,32] we recommend that it is important to increase access to aid in outreach-programmes through: 1) installation of clear and simple criteria and procedures to receive aid; 2) education of beneficiaries about their rights to receive aid; and 3) Checking through interviews with beneficiaries by independent investigators whether donations are properly given. This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure. [1,26]

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We are what we protect
what we stand up for

Chapter 4

Treatment Refusal and Abandonment in Childhood Acute Lymphoblastic Leukemia in Indonesia: an analysis of causes and consequences

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ABSTRACT

Background
Treatment refusal and abandonment are common causes of treatment failure in childhood acute lymphoblastic leukemia (ALL) in many developing countries. In most studies reasons for abandonment were based on the opinion of health-care providers, very few studies have focused on the parental point-of-view. Aims of the study were to analyze the parents' reasons of abandonment and to ascertain the fate of children who abandoned treatment in a pediatric oncology center in Yogyakarta, Indonesia.

Methods
We conducted home-visits to interview families of ALL patients, diagnosed between January 2004 and August 2007, who refused or abandoned treatment.

Results
From January 2004 to August 2007, 159 patients were diagnosed with ALL of which 40 children (25%) refused or abandoned therapy. Thirty-seven (93%) of these children were home-visited. Reasons for abandonment were complex. Most parents mentioned several reasons. Financial and transportation difficulties were not the only, or even the main reasons, for abandonment. Belief of ALL incurability, experience of severe side-effects and dissatisfaction with health-care providers were also important considerations. Most patients (64%) abandoned treatment during the diagnostic-evaluation or remission-induction phase. Of the 37 patients who refused or abandoned treatment, 26 (70%) children died, and 11 (30%) children were still alive, 2 of them more than 2 years after abandonment.

Conclusions
Reducing treatment abandonment of childhood ALL in developing countries requires not only financial and transportation support, but also parental education, counseling and psychosocial support during therapy, improvement of quality-of-care and adequate management of side-effects.

Keywords: cancer, pediatric oncology, treatment refusal or abandonment, reasons, consequences

Abbreviations:
ALL: acute lymphoblastic leukemia
HCP: health-care provider
PEP: parental education program

BACKGROUND

In developed countries, the 5-year survival rate of acute lymphoblastic leukemia (ALL), the most common malignancy in children, has improved in recent years to about 80%[1;2]. However, cure rates are often less than 35% in developing countries. Causes of treatment-failure in developing countries include delayed diagnosis, treatment abandonment, death from toxicity caused by suboptimal supportive care, co-morbid conditions and non-compliance with treatment protocol which leads to increased number of relapses. In many developing countries, this disparity in survival is mainly due to treatment abandonment, a complex problem almost unknown in developed countries[3-10].

Treatment refusal is defined as rejection of any treatment for a potentially curable cancer after a diagnosis is made, and abandonment as missing four or more consecutive weeks of treatment or follow-up while still in therapy. Loss of follow-up refers to missing subsequent appointments once treatment has been completed.[11] Rates of treatment refusal or abandonment of ALL in developing countries vary from 16 to 50%.[8] Abandonment has been associated with low educational and socio-economic status of parents, long travel-time to hospital and non-affordable available treatment. However, these associations are mostly based on medical records studies or on opinions of treating health-care providers (HCP). There is little evidence from families themselves about their reasons for refusal or abandonment.[9]

Our previous study found that treatment refusal or abandonment was the most common cause of treatment failure in Indonesia, where 35% of patients refused or abandoned treatment. There were significant differences in abandonment rates between poor and prosperous patients and between patients having low, intermediate or high education. We found that poor patients received less individualized attention from oncologists and less structured parental education. Most poor patients could not afford treatment and access to donated chemotherapy was inadequate.[12] To increase access to parental education and donations, a structured parental education-program (PEP) was instituted in January 2004, in which families are taught about leukemia, its treatment, possible side-effects and availability of donated chemotherapy for all new ALL parents.

Aims of this study were to interview parents of children who refused or abandoned treatment to solicit their reasons, and to ascertain the fate of children who refused or abandoned treatment.

METHODS

Setting

Our study was conducted at the pediatric department of Dr. Sardjito Hospital, a teaching and tertiary-care referral hospital, in Yogyakarta, Indonesia. Annually aproximately 30-50 children are diagnosed with ALL. The pediatric department consists of a clinic (VIP, 1st, 2nd, and 3rd class) and a policlinic (VIP and general). VIP and 1st class patients can chose their own pediatric oncologist and attend a special VIP policlinic where they are treated by their own personal pediatric oncologist. The second and third class patients go to a general policlinic where they are treated by monthly rotating pediatric residents under the supervision of the pediatric oncologists.

During our research 2 successive ALL protocols were used: the Wijaya Kusuma ALL protocol (January 2004 to December 2005) and the Indonesia ALL 2006 protocol (December 2005 to August 2007). The latter protocol is more intensive: 4 doses of

daunorubicin and 4 doses of L-Asparaginase are added in the induction phase and high-dose methotrexate is added in the consolidation phase. Both protocols used the same risk classification, based upon NCI criteria plus day 8 blast count and patients were thus stratified into standard risk (SR) and high risk (HR). Both protocols consist of an induction, consolidation, and maintenance phase, with an additional re-induction phase for HR patients.

Study design

This was an exploratory descriptive study. We conducted home-visits to interview families of ALL patients who refused or abandoned treatment, diagnosed between January 2004 and August 2007. Home-visits were conducted between September 2007 and January 2008. Respondents gave informed consent to participate and to allow tape-recording. Confidentiality was assured. Semi-structured questionnaires and observations of housing circumstances were conducted by a social pediatrician and psychologist. Interviews focused on reasons for abandonment, parental health-seeking behavior and patients' condition after discontinuing treatment. We observed family circumstances to gain insight about their transportation-difficulties and housing conditions. We classified the housing condition as either poor or good. This classification was based on 3 determinants: floor condition (soil, concrete, or ceramic), quality of cooking facilities (firewood, kerosene, charcoal, or gas) and presence of refrigerator. Families were categorized as having good house condition if at least 2 of the following conditions were present: floor was made of ceramic tile; cooking with electricity or gas; and/or presence of refrigerator. Parental educational status was categorized into low education (no education, elementary school, junior high-school) and high education (senior high-school, academy, university).

The study was approved by the Medical Ethics Committee of Medical Faculty, Gadjah Mada University.

Data Analysis

Frequency distributions, median, means, and standard deviations were assessed for each variable. Data management and analysis were performed by using SPSS for Windows version 12.

RESULTS

Patients' Characteristics

From January 2004 to August 2007, 159 patients were diagnosed with ALL. At the time of analysis on August 2008, 40 (25%) patients had refused or abandoned therapy. There were no significant differences in age, risk stratification, class of hospitalization, parental education level and transport-time between abandonment group (25%) and non-abandonment group (75%). Girls abandoned slightly more often but this difference did not reach statistical significance (Table1).

Thirty-seven families of 40 patients (93%) who refused or abandoned treatment were visited. Two families could not be interviewed due to unclear home-addresses, and 1 family had moved to another island. Duration between interview and abandonment ranged from 1 to 46 months, median 19 months. Twenty-five (68%) respondents mentioned that the decision of treatment refusal or abandonment was made by both parents together. However, they also often mentioned that other persons, on whom they were financially dependent, played an important role in the decision to abandon (Table 1).

Table 1. Demography and medical characteristics

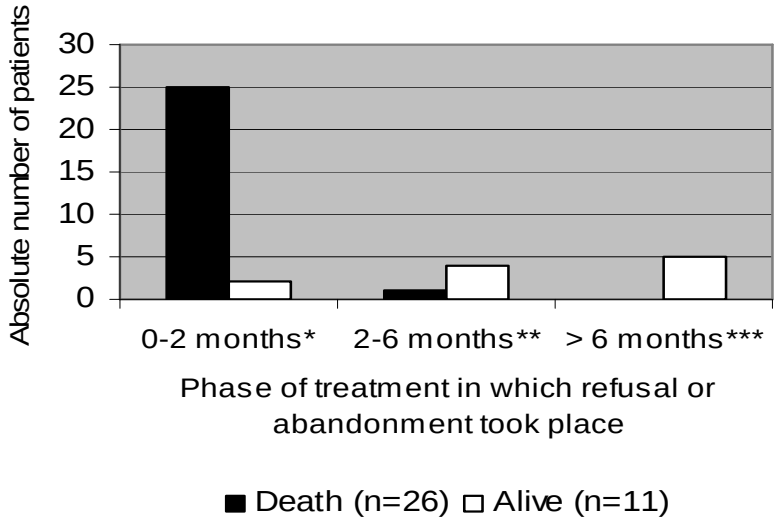
Characteristic	Abandonment group (n=40) n (%)	Non abandonment group (n=119) n (%)	p
Age: mean± SD (years)	5.97±4.3	5.7±3.7	0.77
Gender			
Male	17(43)	88 (57)	0.07
Female	23 (57)	51 (43)	
Risk classification			
HR	23 (57)	61 (51)	0.49
SR	17 (43)	58 (49)	
Class of hospitalization			
VIP and 1st class	5 (12)	22 (18)	0.98
2nd and 3rd class	35 (88)	97 (82)	
Father's education level			
Low (elementary- junior high school)	27 (68)	67 (56)	0.21
High (senior high school – university)	13 (32)	52 (44)	
Mother's educational level			
Low (elementary- junior high school)	27 (68)	66 (56)	0.18
High (senior high school – university)	13 (32)	53 (44)	
Travel time to hospital			
< 1 hour	10 (25)	23 (20)	0.59
2-3 hours	8 (20)	32 (27)	
> 3 hours	22 (55)	62 (53)	
Phase of abandonment			
Diagnostic evaluation	5 (12)		
Remission induction	19 (48)		
Consolidation	5 (12)		
Re-induction	1 (3)		
Maintenance	10 (25)		
Patient's condition at home visit (n=37)			
Alive	11 (30)		
Deceased	26 (70)		
Respondents (n=37)			
Both parents	17 (46)		
Mother	15 (35)		
Father/ others	5 (14)		
Decision of abandonment (n=37)			
Both parents	25 (68)		
Father	5 (14)		
Mother	3 (8)		
Patients	4 (8)		
Father's occupation (n=37)			
Laborer/ irregular job	19 (51)		
Private employee	14 (24)		
Government employee	4 (10)		
Mother's occupation (n=37)			
Laborer/ irregular job/ no work	29 (78)		
Private employee	5 (14)		
Government employee	3 (8)		
Housing condition (n=37)			
poor	33 (89)		
good	4 (21)		
Income: mean (ranged) USD	85 (15 – 400)		

Patient outcomes after abandonment

Of the 37 children who abandoned treatment, 11 (30%) were still alive and looked healthy 1 to 39 months after their last treatment. It was quite surprising that two patients were still alive 2.3 and 3.4 years after their last treatment, which had been given at week 35 and 54 of maintenance phase, which by protocol should last a total of 104 weeks. Of the 37 patients, 26 (70%) died. Twenty five of the 27 patients who refused or abandoned treatment during induction phase died and 1 of the 5 patients who abandoned treatment during consolidation, re-induction and first maintenance phase died. All 5 patients who abandoned treatment during maintenance phase were still alive (Figure 1). Duration between abandonment and death ranged 0-8 months. One patient died en route from the hospital to their house.

Parents perceived that the condition of their children at time of abandonment was good in 16 (43%) respondents, not good in 9 (24%) and very poor in 12 (32%). Some parents of deceased children reported that their children's condition after abandonment looked better for several weeks and became worse only after that period.

Figure 1. Fate of patients per phase of treatment in which refusal or abandonment took place.

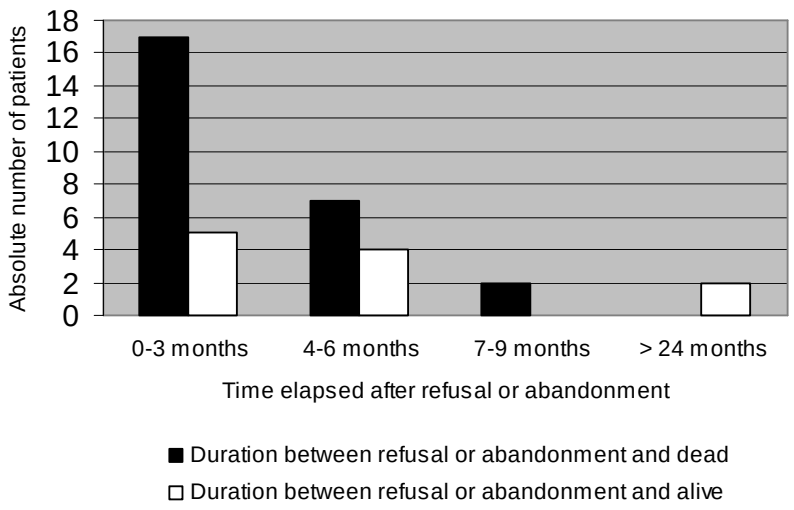


* patients who refused or abandoned treatment during induction phase

** patients who refused or abandoned treatment during consolidation, re-induction and first maintenance phase

*** patients who refused or abandoned treatment during maintenance phase

Figure 2. Fate of patients after treatment refusal or abandonment.



Health seeking behavior

Before being diagnosed as having ALL, all patients visited and were treated by other HCP. Surprisingly, none visited traditional-alternative healers before the diagnosis was made. However, after abandonment all but 3 (n=34) parents reported that they tried to find alternative treatments for their children. Two parents did not take any action because they perceived their child was healthy and one patient died shortly after abandonment. Most of them (n=28, 76%) used traditional herbs and spiritual-religious treatments (n=28, 76%), few parents used massage (n=9, 24%) and paranormal healers (n=5, 13%). Seven of 12 patients who died were taken to other HCP to receive supportive treatment at the end of life.

Reasons for abandonment

Reasons for treatment refusal or abandonment were complex. Most parents mentioned several reasons that fell into 4 main categories: 1) financial and transport difficulties, 2) beliefs about curability and side-effects, 3) children's refusal, and 4) dissatisfaction with health-care providers (Table 2).

Table 2. Reasons cited for treatment refusal or abandonment.

Reasons	n (%)*
Financial difficulties	22 (60%)
Belief that ALL was not curable	22 (60%)
Child's experience of severe side-effects	13 (35%)
Transportation difficulties	8 (22%)
Patient refusal	8 (22%)
Dissatisfaction with health-care providers	4 (11%)
No room available for hospitalization	2 (5%)
Child looked healthy	2 (5%)

* Number of parents that reported the reason; each patient could have more than 1 reason

Financial and transportation difficulties

Most respondents (77%) mentioned that they had financial problems due to the child's illness and 22 (60%) said that this problem was one of the reasons to abandon. However, only 6 (16%) families reported that financial difficulties were the only reason for dropout. Starting in March 2005 the government provided limited insurance for poor families. Most respondents (n=26, 70%) thus had insurance after March 2005, but only 4 (15%) mentioned that the insurance fully covered the costs. They still had to spend money to buy certain drugs (second or third line antibiotics and analgesic-sedatives for lumbar-punctures (LP) and bone-marrow punctures (BMP), and food and toys for their child, accommodation of parents, and transportation.

Most parents (n=28, 76%) did not have a regular income. Family-income decreased after start of child's illness according to 23 parents (62%). During their child's illness, 20 (54%) fathers lost their job because they had to accompany their children to hospital.

Regarding the financial problems, their families, relatives, and religious communities supported them. However, some parents (n=22, 60%) still had debts, and 15 (41%) sold valuables (heritage land and house). Three parents mentioned that only after 3 years they had finally paid off their debts.

Twenty-two (60%) parents said that transportation to hospital was difficult, 24 (65%) parents reported it was time-consuming and expensive. However, only 8 (22%) parents mentioned transportation difficulties as a contributing reason to abandon, and none mentioned that transportation difficulties was the only reason for abandonment. Nine (24%) parents needed more than 5 hours to get from their house to the hospital, and the mean one way transportation-time was 3.1 ± 1.9 hours. Some patients (n=10, 27%) needed to change to connecting buses 5 times or more to reach the hospital.

Health beliefs

Belief about incurability of ALL and children's experience of side-effects were two of the reasons for abandonment, reported by 22 (60%) and 13 (35%) respondents respectively. Parents of patients who refused treatment due to their beliefs about incurability thought that chemotherapy would not result in a better quality-of-life and would only cause side-effects. They believed that alternative treatments were more effective than chemotherapy. Their beliefs were based on stories and experiences of their relatives or from sources such as magazines, newspapers, and internet.

In contrast, parents of patients who abandoned later initially believed that ALL could be cured. However, during the course of treatment they started to doubt it, because they saw patients die from complications. Most patients (26 of 32, 81%) who started treatment suffered from side-effects and most of them (n=15, 58%) perceived their side-effects as moderate to severe. The most common and bothersome side-effect was behavioral alteration: children felt scared, frightened, and traumatized by the medical procedures, according to 24 (66%) parents. Other common and severe side-effects were mouth-ulcers, infection and fatigue. These parents could not face their children suffer during therapy and preferred to have their children live a normal life or die in a peaceful manner.

Parents of a 6 year-old patient who abandoned in week 15 (maintenance phase) and at the time of interview (5 months later) looked healthy and happy, said: "I could not face my child suffer from severe side-effects. She suffered from severe mouth-ulcers,

diarrhea, vomiting and high fever and of course she did not want to eat. She was very scared, angry and cried when doctors or nurses came into her room and she intended to go home. One week at home, after stopping the medication and taking herbal medication she looked better, showing no symptoms at all. Now, she is happier, lives a normal life, and plays with her siblings and friends and next month she will return to school."

Child refusal

Eight patients refused to continue treatment, even though their parents tried to persuade them to continue treatment. All but one of them was older than 10 years. Parents reported that their children shared their experiences, feelings, and beliefs with other similar-aged patients. They believed that chemotherapy could not cure the disease and could even worsen their condition. They did not want to suffer from more side-effects. They were traumatized with medical procedures, especially bone marrow puncture and lumbar puncture. They also believed that their lives and health were in God's-Allah's hands. They felt guilty and did not want to be a financial burden to their family.

Dissatisfaction with health-care providers

Four parents said they were dissatisfied with their doctors and this was one of the reasons to drop-out. They thought that doctors should improve their skills, especially in performing lumbar puncture and bone marrow puncture, and these procedures should be done by oncologists. Parents also asked the interviewers whether there were ways to reduce or prevent pain and traumatic effects of invasive medical procedures.

DISCUSSION

Previous studies were based on expert opinions and found that lack of financial, transportation, essential drugs and local medical facilities were the main contributors to abandonment of therapy in developing countries.[3;6;9-11;13] We actually interviewed families of children who abandoned treatment and found that reasons for abandonment were complex. Financial and transportation problems related to the treatment were major concerns for the parents. Most parents mentioned that they had financial and transportation difficulty. However, only few parents stated that financial difficulty was the only reason for abandonment and none mentioned transportation difficulty as the only reason for abandonment. This finding supported our results that there were no significant differences in class of hospitalization and transport-time between abandonment group and non-abandonment group.

Most parents mentioned several reasons. For example, one parent of a patient who abandoned treatment during the consolidation phase mentioned that besides financial difficulties, the child's condition became worse after receiving chemotherapy. She suffered from severe side-effects, she could not walk anymore, which made her frustrated and bored. They also complained about un-professional young doctors, who failed to perform lumbar puncture. Being a poor family their child was hospitalized in 3rd class ward, and treated by monthly rotating residents, who gave different plans and explanations that confused them. It should be considered that pediatric oncology can not be done by rotating residents, even with good supervision. Children should be taken care of by a pediatric oncologist.

Painful procedures especially LP and BMP were important factors for abandonment. In addition, a traumatic LP with lymphoblasts in the cerebrospinal fluid at diagnosis

can adversely affect the treatment outcome of childhood ALL. [14] Howard et al, 2002 found that performing LP by a less experienced physician increased the risk of a traumatic LP. [15] To reduce patient pain and anxiety and prevent a traumatic LP, this procedure should only be performed by experienced physicians and ideally under short-acting general anesthesia.

Similar to study on pediatric cancer treatment in Malawi, belief of incurability was an important reason for abandonment. [13] We found there were 2 different points of view regarding beliefs of ALL curability. Parents who refused treatment had health beliefs based on "lay resources" such as stories or experiences of relatives, friends or other parents. Unfortunately, they went home immediately after diagnosis, before being exposed to a structured parental education-program. In contrast, parents who abandoned treatment in later weeks initially believed and trusted the information given in a structured parental education-program. However, after their child suffered from severe side-effects and having seen other ALL patients die after receiving chemotherapy they started to weigh the benefits and harms of chemotherapy. This was quite similar to the findings in the study of Kleffens et al [16], and requires a different approach for prevention. For the former group who did not start therapy, a structured parental education-program should be initiated immediately after diagnosis, or better yet, while diagnostic-evaluation is in progress. It is important to conduct non-patronizing, careful and open discussions when alternative medical treatment is proposed by parents or patients. [9;17] For the latter group, a structured parental education-program should be an ongoing process, with regular group meetings of parents and professionals, to discuss their health-beliefs, fears, and experiences on ward. It is important to stress that, once the induction therapy has successfully been completed, the chance of cure in the Yogyakarta situation is already at least twice as high as at initial diagnosis, provided the treatment is not stopped or interrupted. More than half of the events: abandonment, death or no complete remission, take place before or in induction. Besides that, preventing and managing side-effects should be emphasized. HCP should have appropriate knowledge and skills to detect early and treat vigorously any complications that might arise. Supportive care for treating infections and hemorrhage, the most common causes of treatment-related death, should be improved.

Adjusting the protocol based on patients' observations is recommended in life-threatening conditions. It should be considered that most of our patients come from poor financial backgrounds and are malnourished. About 40% fall below 2 standard deviations in weight and height (unpublished observations). Poor nutritional status decreases tolerance of chemotherapy, is associated with altered metabolism of chemotherapy and increased infection rate, resulting in poor clinical outcome.[18;19] Therefore, a simple situation-adjusted protocol based on local conditions is recommended. [20;21]

Some abandonment decisions were made by patients themselves. Adolescent patients decided to stop treatment because they believed that chemotherapy cannot cure the disease but may even worsen their condition. Their belief seemed to be influenced by other similar-aged patients. They shared their experiences, feelings, and beliefs with their peer group. Some of their information came from overhearing the clinical round discussions. It is important that physicians do not discuss patients' condition in front of the patient or other patients. Adolescents may pick up certain aspects of the information and may not be able to put it in the right context. This may create fear and misconceptions amongst them and their peers. Psychosocial support and open

communication between HCP and a peer group of patients may facilitate their coping with the disease and its treatment. [22;23]

Study on pediatric cancer treatment in Malawi found that most parents had visited first a traditional healer before visiting a pediatric center hospital. [13] We found that before abandonment, most families complied with medical advice, and did not visit traditional healers. However after stopping the treatment they tried to find alternative treatments. In general, there were 2 reasons for using alternative treatment: 1) belief that alternative treatment was better than conventional treatment, and 2) a last effort, not to give up, to cure their children. This finding is similar to other studies. [24;25] The most common alternative method used was religious-spiritual. It correlated to their belief that suffering from ALL was destiny, the will of God/Allah. They believed that a religious method would at least improve the children's quality-of-life and that of their families.

CONCLUSION

Treatment refusal and abandonment are still a really big problem in many developing countries. Financial problems, transportation difficulties, beliefs about ALL curability, fear and experience of severe side-effects, child refusal and dissatisfaction with HCP should all be addressed to prevent abandonment. Education programs for parents and communities as well as psychosocial support for parents and patients are recommended. Other important interventions are improvement of supportive care, improvement of knowledge and skills of HCP, better coaching of young residents and prevention and adequate management of severe side-effects.

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Experience is a tough teacher
because it gives a test first
and lessons afterwards

Chapter 5

Parental Experiences of Childhood Leukemia Treatment in Indonesia

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ABSTRACT

In our study we examined socio-economic, treatment-related, and psychological experiences of parents during the acute lymphoblastic leukemia treatment of their children in an academic hospital in Indonesia. Children were treated with the WK-ALL-2000 protocol and received donated chemotherapy. From November 2004 to April 2006, 51 parents were interviewed by psychologists using semi-structured questionnaires. The family income had decreased (69%) since the start of treatment. Parents lost their jobs (29% of fathers, 8% of mothers), most of whom stated that this loss of employment was caused by the leukemia of their child (87% of fathers, 100% of mothers). Treatment-costs resulted in financial difficulties (78%), debts (65%), and forced parents either to postpone or withdraw from parts of treatment (18%). Parents mentioned needing more information (86%) from and contact (77%) with doctors. The parent organization did not pay any visits (69%) during hospitalization, nor did they give information (59%) or emotional support (55%). We have concluded that the socio-economic impact of leukemia treatment was profound. Communication between parents and doctors requires improving. The role of the parent organization was insignificant and must be ameliorated.

Keywords: childhood acute lymphoblastic leukemia, developing country, parental experiences.

INTRODUCTION

Worldwide, the diagnosis of childhood acute lymphoblastic leukemia (ALL) has an important psychological impact on the child and its family, who are faced with a life-threatening illness. [1] In developing countries the diagnosis of childhood leukemia also has an enormous socio-economic impact on most families, who are confronted with high treatment-costs for 2 years. [2-4]

The cure rate of childhood leukemia is as high as 80% in developed countries, and frequently less than 35% in developing nations. A substantial shortfall in survival occurs where there is poverty, poor communication between doctors and patients, and a low standard of parental education. This difference in survival is primarily due to treatment abandonment, an almost unknown problem in developed countries. [5-13] Communication and parental education are of the utmost importance to ensure cooperation and compliance with chemotherapeutic regimens and to prevent treatment abandonment. [2,5,14-19]

Since 1992 there has been close collaboration between pediatric oncology departments in Indonesia and the Netherlands. [3] We found that treatment abandonment was the main cause of treatment failure in our outreach program. Parental education and access to donated chemotherapeutic medicines were lacking. [4] Many health-care providers mentioned that communication between doctors, parents and patients was impeded by strong social hierarchical structures. [20] Starting from January 2004 a parental education program about leukemia, its treatment and availability of donated chemotherapy were introduced. We found that, after introduction of the program, 98% of parents did receive the donated chemotherapy. However, other costs remained: hospitalization expenses, policlinic visits, transportation, loss of daily wages, bone marrow punctures, lumbar punctures, radiographs, blood transfusions and antibiotics. [4,21]

In this study we have investigated the experiences of parents during the leukemia treatment of their children. Socio-economic, treatment-related and psychological aspects have been investigated. The parental perspectives on leukemia treatment may help us to improve our understanding and care of children with cancer in developing countries.

MATERIALS AND METHODS

Setting

Our study was conducted in an Indonesian tertiary care referral clinic Dr Sardjito Hospital in Yogyakarta in Java, where approximately 30-40 children are diagnosed with ALL each year. Childhood ALL is treated according to the WK-ALL-2000 protocol. [3,22]

Study design

This cross-sectional study consisted of a semi-structured questionnaire and was part of a larger questionnaire and more extensive research on compliance with childhood ALL treatment in Indonesia. The focus was to assess socio-economic, treatment-related, and psychological experiences of parents during the leukemia therapy. Participants were parents of childhood ALL patients who were hospitalized or visited

the outpatient clinic at Dr Sardjito Hospital between November 2004 and April 2006. The respondents were interviewed by 3 psychologists. The questionnaire contained statements that parents could evaluate on three or five-point rating scales. A panel of Dutch and Indonesian doctors and psychologists made sure of appropriate, clear and coherent statements. The questionnaire was pilot-tested on a separate group of parents for its content, for the clarity of language and for cultural sensitivities. A few minor adjustments were made on the basis of the pilot-test. Anonymity and confidentiality were guaranteed. The study was approved by the Medical Ethics Committee of Dr Sardjito Hospital.

Data analysis
Data management and analysis were performed with SPSS for Windows version 13.

RESULTS

Patient Characteristics
From November 2004 to April 2006, 72 childhood ALL patients attended Dr Sardjito Hospital. Parents of 51 children (71%) were interviewed. Parents of 21 patients (29%) did not participate, as their children either dropped out (n=10) or died (n=11) before the interview took place. There were no significant differences in age, gender, risk classification, parental educational background and socio-economic status between the respondents (n=51) and non-respondents (n=21).

The 51 children consisted of 32 boys (63%) and 19 girls (37%). Ages ranged from 2 until 16 at diagnosis. In total 29 patients (57%) were diagnosed with Standard Risk leukemia and 22 patients (43%) with High Risk leukemia. At the time of the interview 23 children (45%) were in the first intensive part of chemotherapy (induction, consolidation, reinduction), 25 children (49%) underwent maintenance treatment and 3 children (6%) had completed treatment.

SOCIO-ECONOMIC ASPECTS

Parental educational background
By our definition, low parental education comprised no education, elementary school and junior high school. Intermediate parental education consisted of senior high school and vocational training. High parental education was the result of academy and university training. The educational level of fathers was: low (43%), intermediate (29%), high (27%). The educational level of mothers was: low (35%), intermediate (45%), high (27%).

Parental employment
In total, 23 families (45%) had regular incomes and 28 families (55%) had not. The family income had decreased since the start of treatment according to 35 parents (69%). When the interview was held 46 fathers (90%) and 21 mothers (41%) were in employment. During treatment of their child 15 fathers (29%) lost their jobs, 13 of whom (87%) identified the leukemia of their child as the cause. During ALL treatment 8 mothers (16%) lost their jobs, and all (100%) identified the leukemia of their child as the cause.

Financial difficulties

The costs of treatment resulted in financial difficulties according to 40 parents (78%). These financial difficulties were felt to be a heavy burden according to 36 parents (71%). The costs of treatment resulted in debts according to 33 parents (65%). Parents were forced to request financial help from other family members (n=31; 61%) or their employers (n=4; 8%). The costs of therapy forced 9 parents (18%) either to postpone (n=3) or withdraw (n=6) from parts of treatment. A total of 4 families (8%) did not expect to be able to complete the 2 years of treatment due to financial difficulties and 3 parents (6%) were uncertain about this.

Transportation

Traveling to the hospital (Table 1) was considered expensive (n=30; 59%) and time consuming (n=27; 53%). However, most families (n=28; 55%) did not experience their travel as difficult. Distances to the clinic, the absence of proper transport, and transportation-costs were never reasons to miss hospital appointments according to consecutively 43 (84%), 43 (84%) and 42 (82%) families. During hospitalization of their child parents stayed over at the clinic (n=28; 55%), at home (n=15; 29%), and in home-stays (n=8; 16%).

Table 1. Transportation characteristics of parents (n=51).

Transportation characteristics	N	%
Distance to hospital:		
<30 km	12	24
30-50 km	9	18
>50 km	30	59
Mode of transportation:		
Public transport	27	53
Renting a vehicle	8	16
Private motorbike or car	16	31
Travel time to hospital:		
<1 hour	15	29
1-2 hours	18	35
>2 hours	18	35

School attendance

Of all 51 children, 28 were old enough to attend school. Of these 28 children, 8 children (29%) stopped attending school. The remaining 20 children missed classes: sometimes (n=9; 32%), regularly (n=6; 21%) and frequently (n=5; 18%). Teachers were informed by 27 parents (96%) about the leukemia of their child. Pupils at school were informed about the disease by 17 parents (61%). The school was supportive and helpful according to 22 parents (79%).

TREATMENT-RELATED ASPECTS

Communication with doctors

More information about leukemia and its therapy was necessary according to 44 parents (86%). More contact with doctors was necessary according to 39 parents (77%). Communication with doctors was impeded by differences in status and social hierarchical structures according to 26 parents (51%). Hesitation in asking questions or attention from doctors was felt by 18 parents (35%). Reasons for this hesitation were that doctors seemed too busy (n=17), that parents were afraid that doctors might become irritated (n=7), and that doctors have too high a status (n=5). Doctors determined the topic of conversation according to 17 parents (33%). Doctors did not take time to listen to parents and patients, nor did they answer their questions according to 11 parents (22%).

Parent organization

The existence of a parent organization was important according to 29 parents (57%). The parent organization had not given information according to 30 parents (59%). Members of the parent organization never paid visits during hospitalization of their child according to 35 parents (69%). Meetings of the parent organization were never attended by 36 parents (71%). The parent organization had not given help or emotional support according to 28 parents (55%).

Beliefs about leukemia and its treatment

The health of their child was beyond the doctors' control and was determined by luck, fate or God according to 20 parents (39%), and 8 parents (16%) were uncertain about this statement. Causes of leukemia in their child were: not known or unclear (n=30, 59%), destiny (n=23; 45%), bad luck (n=6; 12%), God's wrath (n=5; 10%). Figure 1 illustrates parental beliefs about the curability of leukemia. Parents reported having confidence in the knowledge (82%) and skills (86%) of doctors.

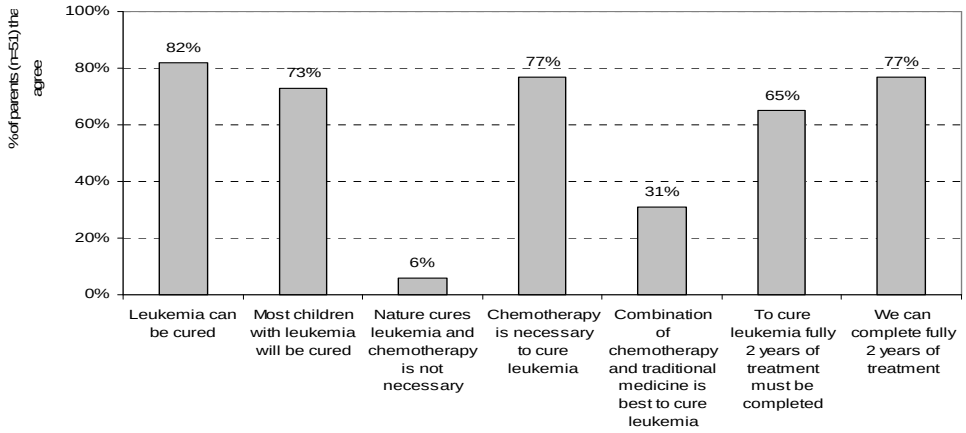

Fig. 1. Beliefs of parents (n=51) about the curability of leukemia.

Traditional or supplementary treatment

Traditional treatment was received by 19 children (37%). Traditional or supplementary methods used were: spiritual counseling (n=19; 37%), massage (n=12; 24%), physiotherapy (n=7; 14%), paranormal help (n=4; 8%) and acupuncture (n=2; 4%). A combination of chemotherapy and traditional medicine was best to cure leukemia according to 16 parents (31%), and 11 parents (22%) were uncertain about this statement.

Medication administration at home

Parents described their compliance with prescribed medicines at home as either good (n=16; 31%) or very good (n=30; 59%). The same person checks medication administration at home according to 39 parents (76%). This person is the mother in most cases (n=32; 63%). Table 2 illustrates reasons for not administering drugs at home. An accumulation of unused tablets was present at home according to 6 parents (12%), and 5 parents (10%) were uncertain about this statement. Difficulties in honestly telling the doctor about their compliance with daily medication intake was admitted by 5 parents (10%), and 1 parent (2%) was uncertain about this statement.

Table 2. Reasons of parents (n=51) for non-compliance with medication administration at home.

Reasons non-compliance medication at home	N	%
Forgetfulness	15	29
Too busy day schedules	4	8
Drugs not available at pharmacy	3	6
Daily medication intake is unnecessary	2	4
Not understanding protocol prescriptions	2	4
Child refuses drugs	2	4

PSYCHOLOGICAL ASPECTS

Marital status

Of all 51 parents, 2 had divorced before the disease was diagnosed. Out of 49 married couples 19 parents (39%) experienced marital problems during the course of treatment of their child. Difficulties in understanding the way their partner coped with stress related to the leukemia of their child were expressed by 13 parents (27%). One couple divorced owing to this. Insufficient emotional support was received from their spouses (n=13; 12%), or given by themselves to their spouses (n=3; 6%). However, in spite of conflicts, the relationship with their spouses actually improved during ALL treatment according to 29 parents (57%).

Coping

The life style of the family had changed considerably due to the illness of their child according to 32 parents (63%). Parents described the emotional condition of their child as unhappy in 14 cases (27%). Parents described their own emotional condition as unhappy in 19 cases (37%). Table 3 shows that 38 parents (75%) were anxious about the condition of their sick child. Parents said that they were preoccupied with fatal return of cancer (n=32; 63%), physical functioning (n=31; 61%), and progressive

disease (n=29; 57%). Parents were positive about the quality of relationship with their child (81%), the openness of communication with their child (74%), and their ability to offer emotional support to their child (79%).

Table 3. Feelings of parents (n=51) toward their ill child.

Parental feelings	N	%
Anxiety	38	75
Hope and optimism	38	75
Acceptance	37	73
Sadness	30	59
Fear	25	49
Depression	11	22
Shame	10	20
Hopelessness	4	8

Siblings

Of the 51 parents, 31 had more than one child. Of these 31 parents, 22 parents (71%) devoted less time and energy to their siblings (71%). Siblings felt neglected by their parents according to 11 parents (35%). Feelings of guilt toward siblings were expressed by 15 parents (48%). Twenty-three parents (74%) were afraid for the well-being of siblings. Nineteen parents (61%) were overprotective toward siblings.

Social support

During the course of treatment the need for social support increased according to 29 parents (57%). In general parents did not receive sufficient social support according to 20 parents (39%). Insufficient social support was provided by the parent organization (n=33; 65%), by the village community (n=16; 31%), by the religious community (n=14; 27%), by colleagues (n=12; 24%), by employers (n=10; 20%), by neighbors (n=6; 12%), by friends (n=3; 6%) and by family (n=1; 2%).

DISCUSSION

In our collaborative project 35% of patients abandon treatment.[4] Communication and parental education are crucial for ensuring cooperation in treatment and for preventing abandonment. This study has shown that parents would like to receive more information about leukemia and its treatment. Strong social hierarchical structures frequently prevented parents from asking for more time and attention from doctors. Therefore it is important that doctors themselves should realize the need of parents for more contact and information. Knowledge and willingness of physicians to provide time, attention and information to parents and patients play significant roles in treatment compliance. Family-focused care is needed, in which families are acknowledged as an active part of the overall treatment. Survival partly depends on the behavior of physicians, parents and patients. [5,10,15,23,24]

The role of the parent organization in the area studied was insignificant. The majority of parents acknowledged the importance of the existence of a parent organization. Yet most parents stated that they had not received information, help or emotional support from the parent organization. Strong parent organizations are not easy to establish,

particularly in developing countries. Serious, social hierarchical status-differences between physicians and parents can hinder the functioning of parent organizations, and it is commonly not accepted that poor parents take on a leading role. As poverty is associated with little education, parents are frequently not capable of fulfilling leadership. Tensions and conflicts can arise when health-care providers and parent organizations have opposed interests. Such conflicts may be completely inappropriate in certain cultures, such as the Javanese. As parents depend on doctors for good care of their child, this may force them to be silent and raise no unrest. Therefore the methods of organizing parent groups must be adjusted to local cultures and needs. Doctors should learn that strong parent organizations are beneficial to the care of children with cancer, and promote their founding. All parties involved must understand that, once strong parent leaders operate and even if disagreements occur, this will eventually contribute to optimal patient care. [25,26]

Most parents were optimistic about the curability of leukemia, although a prior study showed that in fact only 20% of patients survive. [4] Most parents understood that fully 2 years of treatment are necessary and were positive about their ability to complete the 2 years of treatment. Only a minority did not expect to be able to complete the 2 years of treatment due to financial difficulties. In a previous study we learned that the majority of health-care providers also believed that ALL is curable and most health-care providers understood that the total treatment of 2 years needs to be completed. [20] In contrast to the parental perspective, however, the majority of health-care professionals expected most patients not to be able to complete treatment due to financial difficulties.

We learned that the socio-economic impact of the ALL treatment was significant, despite the availability of donated chemotherapy. Many parents became unemployed due to the illness of their child. Prolonged treatment-costs combined with decreased incomes caused most families to experience financial difficulties that resulted in debts.

In contrast to other studies, most parents declared that transportation difficulties were never reasons for missing hospital appointments, although travel time to hospital was >1 hour in 70%, and transportation considered expensive in 59%. [2,6,10,17]

Parents were optimistic about their compliance with medication administration. Parents were positive about the quality of their relationship with their child, the openness of communication with their child, and about their ability to support their child emotionally. Parents also informed school of the disease openly, and felt no taboo on speaking about cancer.

Many parents considered the social support as provided by the village and the religious community, insufficient. This was all the more surprising because this society is known for its strong community feelings where the village, religion and family are concerned. Low social support has been associated with poor emotional health of parents and inadequate psychosocial adjustment. Common reasons for social isolation are that people lack rules for social behavior when contacting families facing life-threatening childhood illness, and that people believe cancer is synonymous with death. Some people avoid meeting the parents of children suffering from leukemia as a means for mitigating the sorrow that the loss of a child entails. [24,26]

A limitation of this study was that answers to the questionnaire may have been influenced because of interviewees giving socially acceptable answers. In Java it is considered inappropriate and disrespectful to criticize. This may have implied that parents considered it more ethical to give impressions that would please the doctors instead of more honest critical remarks. [26] Another limitation was that parents of childhood ALL patients who dropped-out or died, were not interviewed. This may partly mean that the more compliant parents participated in this study. Currently, interviews with families whose children abandoned treatment do take place.

Summarizing, what have we learned from the parental perspectives on childhood leukemia treatment? This study has shown that the socio-economic impact of leukemia treatment is profound. Communication between parents and doctors ought to be improved. Parents need more contact with and information from doctors. The role of the parent organization must be ameliorated.

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You did then
what you knew how to do
Now you know better
you do better

Chapter 6

Comparing Childhood Leukaemia Treatment Before and After Introduction of a Parental Education Program in Indonesia

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Submitted.

ABSTRACT

Setting Previously, we found that childhood acute lymphoblastic leukaemia (ALL) treatment results in Indonesia differed significantly between poor and prosperous patients. There was a striking disparity in the way treatment was provided to poor, as opposed to prosperous, patients. Poor patients received less individualized attention from oncologists. Access to parental education and donated chemotherapy was lacking.

Intervention Starting from January 2004, a structured parental education program for all parents, poor and prosperous, was introduced to improve access to parental education and donated chemotherapy. The program contained a video-presentation in hospital, information-booklet, DVD, audiocassette, informed-consent, statement-of-understanding for donated chemotherapy, and complaints-procedure.

Objective Our study compared childhood ALL treatment outcome before and after introduction of the parental education program.

Design We reviewed medical records of 283 children with ALL diagnosed during two periods: before (1997-2002; n=164) and after (2004-2006; n=119) introduction of the education program. Data on treatment results and parental socioeconomic status were collected.

Results After introduction of the education program, treatment refusal decreased significantly and event-free survival increased significantly in poor patients. Treatment abandonment increased significantly in prosperous patients. In the overall population toxic-death increased significantly and no significant difference in event-free survival was found.

Conclusions After introduction of the education program, poor families received structured information about leukaemia, treatment, and donated chemotherapy for the first time. Treatment refusal decreased and event-free survival increased significantly in poor patients. To improve survival significantly in the overall population too, it is important that toxic-death and treatment abandonment decrease as causes of treatment failure. Improvement of knowledge, skills and communication of doctors is required to manage treatment toxicity and prevent treatment abandonment. Treatment intensity should be matched with possibilities of supportive-care.

The cure-rate of childhood acute lymphoblastic leukaemia (ALL), the most common cancer in children, is about 80% in developed countries, and frequently less than 35% in developing nations. This difference is believed to be primarily due to treatment refusal or abandonment, an almost unknown problem in developed countries. [1,2] Few countries reported reduction in treatment refusal or abandonment due to twinning-programs. In twinning, public hospitals in developing countries and established cancer centres elsewhere cooperate to improve survival among children with cancer. [1,2-4] A twinning-program between Brazil and USA showed that installing a dedicated paediatric-oncology unit, therapeutic protocols, trained nurses, 24-hr-on-site physician-coverage and intensive-care reduced drop-out from 16% to 0.5% in 10 years.[1,2] A twinning-program between Nicaragua and Italy illustrated that trained doctors and nurses, therapeutic protocols, research involvement and financial help for clinic and parent-house construction reduced drop-out from 20% to 7% in 16 years.[2,3]

In our twinning-program between Indonesia and the Netherlands, we found [5] that treatment results in Indonesia differed significantly between 164 children with different socioeconomic backgrounds, even though children were treated in the same hospital with the same protocol. Treatment refusal or abandonment occurred in 47% of 120 poor and 2% of 44 prosperous patients. Event-free survival occurred in 11% of poor and 45% of prosperous patients. There was a striking disparity in the way treatment was given to poor, as opposed to prosperous patients. Poor patients received less individualized attention from oncologists. Parental education about leukaemia, treatment, and the possibility of receiving donated chemotherapy from Dutch charity was lacking. [5] There were no clear criteria for families to receive donated chemotherapy. It was assumed that oncologists informed all families that their children could receive part or all chemotherapy for free, if required. However in practice, only 27 patients (16%) were informed about this possibility. Most patients (n=137, 84%) were not informed at all and had to pay for donated chemotherapy. Many poor parents could not afford the expensive medicines and treatment costs, and refused or abandoned treatment of their children. [6] These results taught us that access to parental education and donated chemotherapy for the poor had to be improved.

Starting from January 2004, a parental education program for all parents, poor and prosperous, was introduced in Yogyakarta. This program aimed to increase access of poor patients to information about leukaemia, treatment and donated chemotherapy. We hypothesized that increased access would importantly decrease treatment refusal or abandonment and increase event-free survival in poor patients. Because prosperous patients already had access to information about ALL from their personal oncologists and could afford required chemotherapy before introduction of education program, we did not expect their treatment results to differ much after introduction of the program.

The objective of this study was to compare childhood leukaemia outcome before and after introduction of the parental education program.

METHODS

Setting

Indonesia has about 218 million inhabitants. Like in other low-income countries, an immense gap exists between the poor majority and privileged minority. Literacy is around 92%.[7] Indonesia has approximately 2000-3200 new childhood ALL cases annually.[8] Our study is conducted in academic Dr Sardjito Hospital in Yogyakarta, where 30-50 children are diagnosed with ALL each year.[9] The paediatric department distinguishes four classes: third, second, first, and VIP. With increasing rank, ward conditions improve and number of children per hospital-room decreases. Two polyclinic types are distinguished: general and VIP. Most patients attend second/ third class wards (operated by junior-residents who are daily supervised by oncologists) and general polyclinic (staffed by junior-residents with no experience in the field and only supervised at their request). Patients who attend VIP/ first class wards (operated by senior-residents who are daily supervised by oncologists) and VIP polyclinic (staffed by oncologists) have
same oncologist throughout treatment. During 2005 a limited health-insurance card was instituted in Indonesia, which was supposed to cover part of hospital-costs for the poorest. However, governmental health-insurance plans changed continuously and it has been unclear which costs were covered. After health-insurance institution, oncologists intensified treatment somewhat in 2005 and introduced new protocol with even higher intensity in 2006. Oncologists hoped that adding more and higher doses of chemotherapy, now paid by insurance, might decrease the relapse-rate.

Parental education program

Starting from January 2004, one social paediatrician provided the parental education program at diagnosis. This paediatrician invited parents to watch video-presentation together and ask questions. The video-presentation ensured that poor and prosperous parents received same information: a paediatric-oncologist explained disease and treatment. Parents were informed about donated chemotherapy from Estella Fund. Clear rules were explained: all childhood ALL patients were entitled to receive methotrexate, vincristine, daunorubicin and L-asparaginase for free. For 6-mercaptopurine 0.04 USD was charged. Parents had to pay dexamethasone (0.04 USD) themselves. In practice this meant that parents paid 0.04 USD instead of 1 USD per day for chemotherapy. (Parents still paid hospitalization costs, policlinic visits, transportation, loss of daily wages, bone-marrow/ lumbar punctures, radiographs, blood transfusions, antibiotics. Insight into the extent of additional costs in developing countries is lacking and requires future studies.) A complaints-procedure was installed. Parents were given opportunities to communicate or complain about donations with Estella Fund by mail or e-mail. Informed-consent and Estella Fund statements-of-understanding were introduced. Parents, patients, survivors and parent organization representatives encouraged parents to comply with treatment and not drop-out. In addition to this video-presentation, parents received an information-booklet, DVD, and audiocassette containing the same information. [13]

Study design
Included were all children (0-16 years) with newly diagnosed ALL. Medical records were studied of patients diagnosed during two periods: before (January 1997- August 2002) and after (January 2004- December 2006) introduction of the parental education program.

Children were treated by: COM-ALL protocol (1997-1999), WK-ALL protocol (1999-2005), Indonesia-ALL protocol (2005-2006). All protocols used the same risk-stratification and contained induction (6 weeks), consolidation (5 weeks), continuing therapy (96 weeks), with additional re-induction therapy (6 weeks) for high-risk patients. Total treatment takes two years.

Patient characteristics and treatment results were noted. Treatment failure was defined as refusal or abandonment of treatment, treatment-related death, and progressive or relapsed leukaemia. Treatment refusal was defined as rejection of any therapeutic intervention. Treatment abandonment was used if therapy was initiated but not completed. Our socioeconomic status classification divided children as coming from poor or prosperous families, based on 2 determinants: monthly income level of parents and assigned hospital class during diagnostic process. Both determinants are obtained routinely during hospital admission and recorded in medical records. The threshold of monthly income for poor versus prosperous families was set at 80 USD before and 100 USD after introduction of education program. Patients attending VIP/ first class wards and VIP polyclinic were classified as prosperous. Patients attending second/ third class wards and general polyclinic were classified as poor.

The study was approved by the Medical Ethics Committee of Gadjah Mada University.

Data Analysis
Data management and analysis were performed by SPSS version 12. Differences in patient characteristics and treatment outcome before and after introduction of the education program were compared using chi-squared test, Fisher's Exact test and t-test. Only outcome during first two years (duration to complete treatment) was considered in this comparison to avoid bias caused by different follow-up times in the two periods. Probability of event-free survival was estimated by Kaplan-Meier method; estimates were compared using log-rank test. Event-free survival was measured from date when patient received diagnosis of leukaemia to first treatment-failure (refusal or abandonment of treatment, treatment-related death, progressive or relapsed leukaemia) or date of last follow-up. The most recent follow-up on treatment outcome was December 2008. Cox proportional hazards model evaluated effect of treatment period, socioeconomic status, risk-stratification and gender on risk of treatment failure.

RESULTS

We reviewed medical records of 283 children with ALL diagnosed during two periods: before and after introduction of the parental education-program.

From January 1997 to August 2002 (before introduction education program), 164 patients received diagnosis of ALL. Twenty-one (13%) patients did not start therapy, 36 (22%) followed COM-ALL protocol, and 107 (65%) WK-ALL protocol.

From January 2004 to December 2006 (after introduction education program), 119 patients received diagnosis of ALL. Six patients (5%) did not start therapy, 74 (62%) followed WK-ALL protocol, and 39 (33%) Indonesia-ALL protocol.

No significant differences in age, gender, socioeconomic status and risk-stratification were found in children before (n=164) and after (n=119) introduction of the education program.

Table 1 shows outcome at 2 years after diagnosis in overall population before (n=164) and after (n=119) introduction of the parental education program. Treatment refusal in overall population decreased significantly (P=0.010) after introduction of the parental education program. Difference in treatment abandonment between the two periods was not significant. Treatment-related death increased significantly (P=0.017) after introduction of the parental education program. No significant difference in event-free survival estimates in overall population was found before and after introduction of education program. Hazard-ratios for treatment failure were 1.4 (95% CI, 1.1-1.8) for early versus recent period, 2.6 (95% CI, 1.8-3.7) for poor versus prosperous population, 1.8 (95% CI, 1.4-2.4) for high-risk versus standard-risk ALL, and 0.9 (95% CI, 0.7-1.2) for male versus female gender.

Table 1. O**utcome at 2 years after diagnosis of overall population before (n=164) and after (n=119) introduction of the parental education program.**

	Before introduction parental education program (n=164)	**After introduction parental education program (n=119)**	***P* value comparing 2 periods**
Treatment refusal	18 (11%)	3 (3%)	0.010
Treatment abandonment	39 (24%)	28 (24%)	ns
Treatment-related death	38 (23%)	43 (36%)	0.017
Progressive or relapsed leukaemia	30 (18%)	8 (7%)	0.005
Event-free survival	39 (24%)	37 (31%)	ns

Table 2 shows outcome at 2 years after diagnosis in poor population before (n=120) and after (n=96) introduction of the parental education program. Treatment refusal in poor population decreased significantly (*P*=0.001) after introduction of the parental education program: 2% of 96 poor patients refused treatment, as opposed to 14% of 120 poor patients in the past. Difference in treatment abandonment between the two periods was not significant. Figure 1 shows significant improvement of event-free survival estimates in poor population after introduction of education program (*P*=0.004).

Table 2. O**utcome at 2 years after diagnosis of poor population before (n=120) and after (n=96) introduction of the parental education program.**

	Before introduction parental education program (n=120)	**After introduction parental education program (n=96)**	***P* value comparing 2 periods**
Treatment refusal	17 (14%)	2 (2%)	0.001
Treatment abandonment	39 (33%)	25 (26%)	ns
Treatment-related death	30 (25%)	34 (35%)	ns
Progressive or relapsed leukaemia	18 (15%)	7 (7%)	ns
Event-free survival	16 (13%)	28 (29%)	0.004

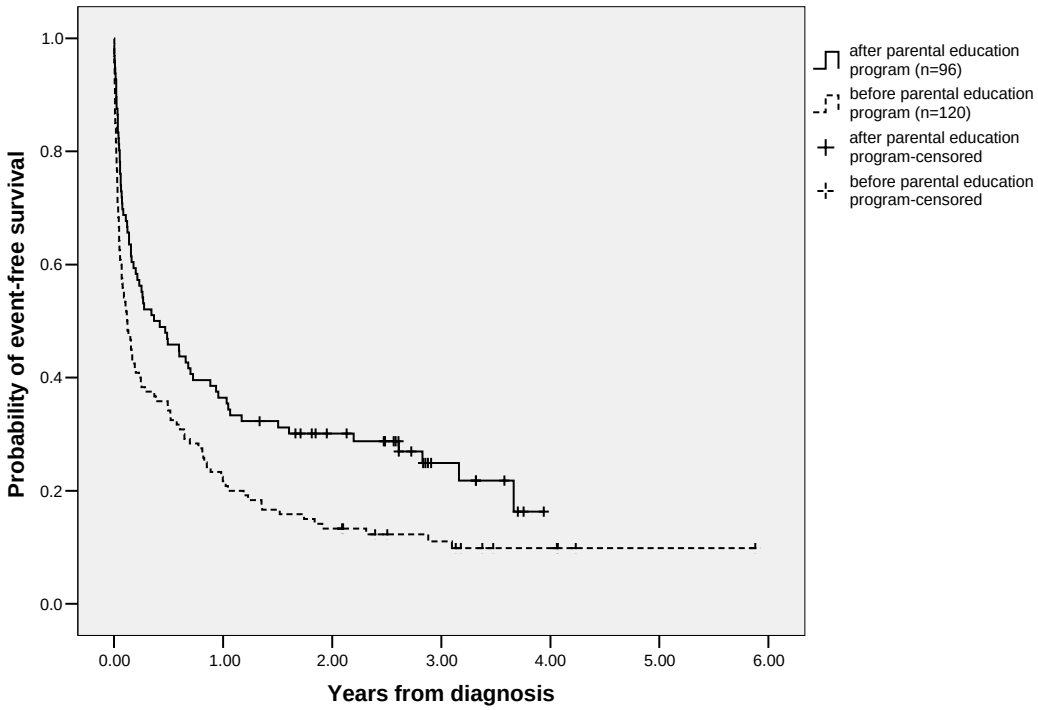

Figure 1. Kaplan-Meier estimates of event-free survival of poor population before (n=120) and after (n=96) introduction of the parental education program (*P*=0.004). Events included refusal or abandonment of treatment, treatment-related death, and progressive or relapsed leukaemia.

Table 3 shows outcome at 2 years after diagnosis in prosperous population before (n=44) and after (n=23) introduction of the parental education program. Difference in treatment refusal between the two periods was not significant. Treatment abandonment in prosperous population increased significantly (*P*=0.037) after introduction of the parental education program: 13% of 23 prosperous patients abandoned treatment, as opposed to no one of 44 prosperous patients in the past. Figure 2 shows no significant difference in event-free survival estimates in prosperous population before and after introduction of education program.

Table 3. O**utcome at 2 years after diagnosis of prosperous population before (n=44) and after (n=23) introduction of the parental education program.**

	Before introduction parental education program (n=44)	**After introduction parental education program (n=23)**	***P* value comparing 2 periods**
Treatment refusal	1 (2%)	1 (4%)	ns
Treatment abandonment	0 (0%)	3 (13%)	0.037
Treatment-related death	8 (18%)	9 (39%)	ns
Progressive or relapsed leukaemia	12 (27%)	1 (4%)	0.026
Event-free survival	23 (52%)	9 (39%)	ns

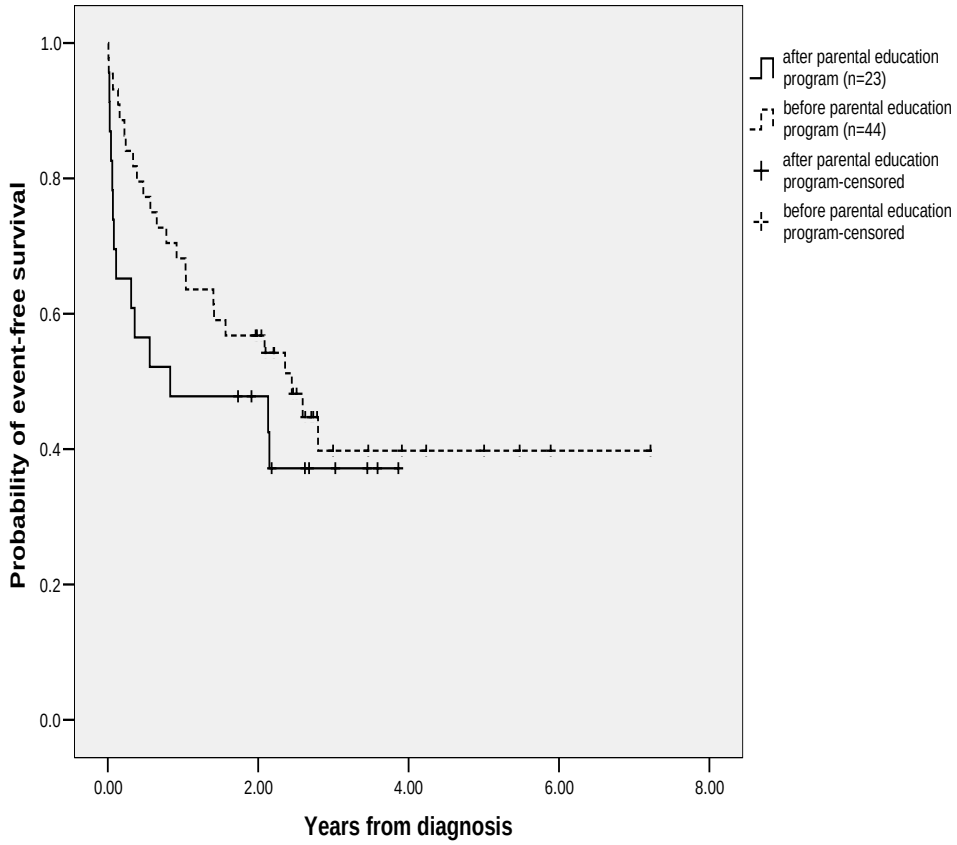

Figure 2. **Kaplan-Meier estimates of event-free survival of prosperous population before (n=44) and after (n=23) introduction of the parental education program (*P*=ns). Events included refusal or abandonment of treatment, treatment-related death, and progressive or relapsed leukaemia.**

DISCUSSION

Before introduction of the structured parental education program, information about leukaemia, treatment and availability of external funding was seldom given to poor families. Residents provided parental education for the poor. However, residents lacked experience in paediatric-oncology and knowledge about funds; consequently, information was not complete. Strong social hierarchical structures hindered communication between doctors and poor parents. As a result, many parents did not understand why it was important for children to take their medication daily during 2 years. [5] Most parents could not afford prolonged treatment costs and had no access to donated chemotherapy. [6] Not all health-care providers believed it possible to cure poor patients with leukaemia, which requires an expensive, prolonged treatment. [5] Most health-care providers believed that prosperous patients complied better with

treatment and that doctors comply better with treatment for prosperous patients. We warned for a self-fulfilling prophecy. If doctors expect poor families to perform less, their own input may decrease and subsequently compliance of parents and patients may diminish and lesser performance and treatment results evolve. [10]

Starting from January 2004, a parental education program for all parents, poor and prosperous, was introduced to increase access of poor patients to information about leukaemia, treatment and donated chemotherapy. [6] We hypothesized that increased access would importantly decrease treatment refusal and abandonment and increase survival in the poor. Our study partially confirmed this hypothesis. After introduction of the education program treatment refusal decreased significantly, treatment abandonment decreased but not significantly, and event-free survival improved significantly in poor children. This teaches us that our parental education program has been able to inform and encourage parents to start treatment, but has not sufficiently been able to make patients complete treatment. It illustrates that showing interest, investing time, willingness to provide information, and giving donated chemotherapy to poor families are potentially able to increase compliance and improve survival of poor patients.

Because prosperous patients already had access to information about ALL from their personal oncologists and could afford the required chemotherapy before introduction of the education program, we did not expect their treatment outcome to differ much after introduction of the program. However, we did find that prosperous patients abandoned treatment more frequently after introduction of the education program. To understand this increase some background information is required: After institution of limited health-insurance in 2005, oncologists intensified treatment. Therefore toxicity also increased. From interviews with dropped-out families[11] we learned that prosperous patients abandoned treatment due to fear of toxicity. After seeing severe side-effects in their child or other children die on wards after having received chemotherapy, parents decided to stop treatment.

Treatment-related death increased significantly in the overall population. Several factors may have contributed: 1) Now that less patients drop-out more patients are at risk to die of treatment-related toxicity. 2) Use of intensified and more toxic chemotherapy leads to increased chance of toxic-death, if supportive-care facilities do not keep pace with this intensification. Most patients are poor and malnourished. Poor nutritional status decreases tolerance of chemotherapy, alters metabolism of chemotherapy, and is associated with increased infection-rate, resulting in poor clinical outcome. [12] Protocol adjustments based on patients' observations are recommended in life-threatening conditions. Doctors must improve their knowledge and skills to detect and vigorously treat complications, as early as possible. Health-care providers need an education program about handling treatment toxicity. Intensity of treatment should be matched with possibilities of supportive-care. [13,14] 3) Recent increase in hospital admittances. Long waiting-lists for hospitalization resulted in delays in leukaemia treatment administration according to protocol. Immune-compromised leukaemia patients in overcrowded hospital rooms were more at risk to develop potentially fatal infections. To solve this problem, a new paediatric-oncology ward will be build with the help of charities.

Although treatment refusal in the poor and overall population decreased significantly, the problem remains that substantial numbers of poor and prosperous patients refuse or abandon treatment. From our previous study [11] in which dropped-out families were interviewed, we learned that reasons for drop-out were complex and multiple. Financial problems, transportation difficulties, beliefs about ALL incurability, fear and experience of severe side-effects, and dissatisfaction with doctors played a role. Parents who refused treatment had health beliefs based on "lay resources", such as stories of relatives, friends or other parents. Unfortunately, they went home immediately after diagnosis, before being exposed to the education program. In contrast, parents who abandoned treatment initially trusted information presented in the education program. However, after their child suffered from severe side-effects and seeing other ALL patients die after receiving chemotherapy, they started to weigh the costs and harms of chemotherapy. [11] From the families who refused treatment, we learned that education programs should be initiated during diagnostic evaluation. From the families who abandoned treatment, we learned that education programs should be an ongoing process, with regular group meetings of parents and professionals, to discuss health beliefs, fears, and experiences on wards. Awareness must grow that communication with all families, poor and prosperous, is essential. Doctors themselves have an important influence on compliance, drop-out, and survival of children with ALL. [1,15-18] The recommended education program for health-care providers should therefore not only aim at improving knowledge and skills, but must also emphasize the significant impact that showing interest, providing information, checking whether information has been understood, and the training of proper communication skills can have.

Historical analyses have weaknesses. Without some control or randomization, they cannot really demonstrate that results are only due to the intervention. This weakness applies to our parental education program about leukaemia and the donations too. We can mention a few considerations. Maybe the introduction of the limited health-insurance card for the poorest in 2005, although unstable and unclear, has encouraged some poor families to follow treatment. Maybe the intensified treatment in 2005 and 2006 contributed to treatment-related death and treatment abandonment. Maybe more families have been able to take treatment, now that the Asian economic crisis of 1997 no longer takes its toll. Maybe the recent waiting-lists for hospitalization influenced treatment results. Maybe doctors have improved or gotten worse over time. Also the small number of prosperous patients limits the interpretation of our results.

We conclude that after introduction of the parental education program poor families received structured information about leukaemia, treatment and donated chemotherapy for the first time. Treatment refusal decreased and survival increased significantly of poor patients. However, work remains to be done. To improve survival, it is important that toxic-death and treatment abandonment decrease as causes of treatment-failure. Improvement of knowledge, skills and communication of doctors is required to manage treatment toxicity and prevent treatment abandonment. Treatment intensity should be matched with possibilities of supportive-care.

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Facts do not cease to exist
because they are ignored

Aldous Huxley

IV. SUMMARY

The survival rate of childhood acute lymphoblastic leukemia (ALL), the most common cancer in children, is as high as 80% in developed countries but frequently is <35% in developing nations. This difference is believed to be attributable primarily to refusal or abandonment of treatment, both of which are almost unknown in developed countries.

Treatment refusal or abandonment constitutes one end of the non-compliance spectrum, which ranges from occasional lapses to total withdrawal. Failure to adhere to treatment is not restricted to patients and parents, but can also concern physicians.

Aims of this study are:
1) To examine the influence of socio-economic status on childhood ALL treatment and treatment refusal or abandonment in a developing country.
2) To investigate parental experiences during childhood ALL treatment and their reasons to refuse or abandon treatment.
3) To determine whether a structured parental education program increases the access to donated chemotherapy and decreases treatment refusal or abandonment.

A major reason for poor survival of childhood acute lymphoblastic leukemia in developing countries is treatment refusal or abandonment. This can be associated with parental socioeconomic status and attitudes of health care providers. In **Chapter 1** we examined the influence of 2 socioeconomic status determinants, parental income and education, on treatment in an Indonesian academic hospital. Medical charts of 164 patients who received a diagnosis of acute lymphoblastic leukemia between January 1997 and August 2002 were abstracted retrospectively. Data on treatment results and parental financial and educational background were collected. Open interviews were conducted with 17 parents and 21 health care providers. Of all patients, 35% refused or abandoned treatment, 23% experienced treatment-related death, 22% had progressive or relapsed leukemia, and 20% had an overall event-free survival. Treatment results differed significantly between patients with different socioeconomic status; 47% of poor and 2% of prosperous patients refused or abandoned treatment. Although poor and prosperous patients used the same protocol, the provided treatment differed. Poor patients received less individualized attention from oncologists and less structured parental education. Strong social hierarchical structures hindered communication with doctors, resulting in a lack of parental understanding of the necessity to continue treatment. Most poor patients could not afford treatment. Access to donated chemotherapy also was inadequate. Treatment refusal or abandonment frequently resulted. There was no follow-up system to detect and contact dropouts. Health care providers were not fully aware that their own attitude and communication skills were important for ensuring compliance of patients and parents.

Based on these findings a structured parental education program about leukemia, its therapy, donated chemotherapy and compliance was designed. Starting from January 2004 this program has been provided to all parents. The program contained: a video-presentation in hospital, information booklet, audiocassette, DVD, procedures for

informed-consent, statement of understanding for donated chemotherapy and a complaints-mechanism.

Chapter 1 illustrated that treatment results differed significantly between poor and prosperous children with leukemia in Indonesia. In **Chapter 2** we determined whether parental socio-economic status influences beliefs, attitude and behavior of health-care providers treating childhood leukemia in Indonesia. A self-administered semi-structured questionnaire was filled in by 102 health care providers (69 doctors, 28 nurses, 2 psychologists, 2 hematology technicians, 1 administrator) from November 2004 till August 2005. We found that most health care providers (98%) asked parents about their financial situation. The decision to start treatment was influenced by parental socio-economic status (86%), motivation of parents (80%), and motivation of doctors (76%). Health care providers stated that prosperous patients comply better with treatment (64%), doctors comply better with treatment for the prosperous (53%), most patients cannot afford to complete treatment (58%), less extensive explanations are given toward poor families (60%), and communication is impeded by differences in status (67%). When dealing with prosperous families a minority of health care providers stated that they pay more attention (27%), work with greater accuracy (24%), take more interest (23%), and devote more time per visit (22%). Most health care providers denied differences in the quality of medical care (93%) and the chances of cure (58%) between poor and prosperous patients. We concluded that beliefs, attitude and behavior of health care providers toward poor versus prosperous patients appeared to differ. These differences may contribute to the immense drop-out rate and slight chances of survival among poor leukemia patients in developing countries.

In Chapter 1 we described that the access to donated chemotherapy for childhood leukemia patients in Indonesia was limited from 1997 until 2004: only 16% of eligible families received donations. After the introduction of our structured parental education programme in January 2004, we examined in **Chapter 3** the access of parents of children with leukemia to donated chemotherapy. Of 72 new childhood ALL patients attending the Indonesian academic hospital from November 2004 till April 2006, 51 parents (71%) were interviewed by independent psychologists using semi-structured questionnaires. Parents of 21 patients (29%) did not participate because their children dropped-out (n = 10) or died (n = 11) before an interview took place. Four patients had health insurance and did not need donated chemotherapy. Access to donated chemotherapy was improved: 46/47 patients (98%) received donations. Structured parental education improved the access to donated chemotherapy. Outreach-programs may benefit from this approach. This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure.

Treatment refusal and abandonment are common causes of treatment failure in childhood acute lymphoblastic leukemia (ALL) in many developing countries. In most studies reasons for abandonment were based on the opinion of health care providers, very few studies have focused on the parental point-of-view. Aims of the study in **Chapter 4** were to analyze the parents' reasons of abandonment and to ascertain the fate of children who abandoned treatment in a pediatric oncology center in Yogyakarta, Indonesia. We conducted home-visits to interview families of ALL patients, diagnosed between January 2004 and August 2007, who refused or abandoned treatment. During this period, 159 patients were diagnosed with ALL of

which 40 children (25%) refused or abandoned therapy. Thirty-seven (93%) of these children were home-visited. Reasons for abandonment were complex. Most parents mentioned several reasons. Financial and transportation difficulties were not the only or main reasons for abandonment. Belief of ALL incurability, experience of severe side-effects and dissatisfaction with health care providers were also important considerations. Most patients (64%) abandoned treatment during the diagnostic-evaluation or remission-induction phase. Of the 37 patients who refused or abandoned treatment, 26 (70%) children died, and 11 (30%) children were still alive, 2 of them more than 2 years after abandonment. We concluded that reducing treatment abandonment of childhood ALL in developing countries requires not only financial and transportation support, but also parental education, counselling, psychosocial assistence, improvement of quality-of-care and adequate management of side-effects.

In **Chapter 5** we examined socio-economic, treatment-related, and psychological experiences of parents during the acute lymphoblastic leukemia treatment of their children in an academic hospital in Indonesia. Children were treated with the WK-ALL-2000 protocol and received donated chemotherapy. From November 2004 to April 2006, 51 parents were interviewed by psychologists using semi-structured questionnaires. The family income had decreased (69%) since the start of treatment. Parents lost their jobs (29% of fathers, 8% of mothers), most of whom stated that this loss of employment was caused by the leukemia of their child (87% of fathers, 100% of mothers). Treatment-costs resulted in financial difficulties (78%), debts (65%), and forced parents either to postpone or withdraw from parts of treatment (18%). Parents mentioned needing more information (86%) from and contact (77%) with doctors. The parent organization did not pay any visits (69%) during hospitalization, nor did they give information (59%) or emotional support (55%). We have concluded that the socio-economic impact of leukemia treatment was profound. Communication between parents and doctors requires improving. The role of the parent organization was insignificant and must be ameliorated.

In **Chapter 6** we compared childhood ALL treatment outcome before and after introduction of the parental education program. We reviewed medical records of 283 children with ALL diagnosed during two periods: before (January 1997- August 2002; n=164) and after (January 2004-December 2006; n=119) introduction of the education program. Data on treatment results and parental socioeconomic status were collected. After introduction of the education program, treatment refusal decreased significantly and event-free survival increased significantly in poor patients. Treatment abandonment increased significantly in prosperous patients. In the overall population toxic-death increased significantly and no significant difference in event-free survival was found. We concluded that after introduction of the education program, poor families received structured information about leukemia, treatment, and donated chemotherapy for the first time. Treatment refusal decreased and event-free survival increased significantly in poor patients. To improve survival significantly in the overall population, it is important that toxic-death and treatment abandonment decrease as causes of treatment failure. Improvement of knowledge, skills and communication of doctors is required to manage treatment toxicity and prevent treatment abandonment. Treatment intensity should be matched with possibilities of supportive-care.

Good character is more to be praised than outstanding talent. Most talents are, to some extent, a gift. Good character, by contrast, is not given to us. We have to build it piece by piece - by thought, choice, courage and determination.

V. SAMENVATTING

De overlevingskans van acute lymfatische leukemie (ALL) in kinderen, de meest voorkomende vorm van kanker bij kinderen, bedraagt ongeveer 80% in meer ontwikkelde landen en meestal minder dan 35% in ontwikkelingslanden. Dit verschil wordt in belangrijke mate toegeschreven aan het weigeren of voortijdig verlaten van de behandeling. Beide fenomenen zijn niet of nauwelijks bekend in meer ontwikkelde landen.

Het weigeren of voortijdig verlaten van de behandeling is een vorm van therapie-ontrouw. Therapie-ontrouw varieert van het zich af en toe niet houden aan therapie voorschriften tot het totaal weigeren of stoppen van de behandeling.

Doelen van ons onderzoek zijn:
1) Bestuderen van de invloed van de sociaal-economische status op de behandeling van kinderleukemie en op het weigeren of voortijdig verlaten van de behandeling.
2) Onderzoeken van de ervaringen van ouders tijdens de behandeling van kinderleukemie en hun beweegredenen om de therapie te weigeren of voortijdig te verlaten.
3) Bepalen of een gestructureerd oudervoorlichtingsprogramma de toegang tot gedoneerde cytostatica vergroot en het weigeren of voortijdig verlaten van de behandeling doet afnemen.

Een belangrijke reden voor de kleine overlevingskans van acute lymfatische leukemie bij kinderen in ontwikkelingslanden is het weigeren of voortijdig verlaten van de behandeling. Dit kan geassocieerd worden met de sociaal-economische status van ouders en de houding van ziekenhuispersoneelsleden. In **Hoofdstuk 1** hebben wij de invloed onderzocht van 2 sociaal-economische determinanten, het inkomens- en opleidingsniveau van ouders, op de behandeling in een Indonesisch academisch ziekenhuis. Medische dossiers werden bestudeerd van 164 patiënten die tussen januari 1997 en augustus 2002 werden gediagnostiseerd met ALL. Gegevens over de behandelingsresultaten en de financiële en opleidings-achtergrond van ouders werden verzameld. Open interviews werden gehouden met 17 ouders en 21 ziekenhuis personeelsleden. Van alle patiënten, weigerde of verliet 35% de behandeling, stierf 23% ten gevolge van de behandeling, was er in 22% sprake van progressie of terugkeer van de ziekte, en had 20% een incident-vrije overleving. Behandelingsresultaten verschilden significant tussen patiënten met verschillende sociaal-economische status: 47% van de arme en 2% van de meer welvarende patiënten weigerden of verlieten voortijdig de behandeling. Alhoewel arme en meer welvarende patiënten werden behandeld met hetzelfde protocol, verschilden de implementatie van de behandeling en de behandelinggsresultaten opmerkelijk tussen arme en meer welvarende patiënten. Arme patiënten kregen minder geïndividualiseerde aandacht van oncologen en minder oudervoorlichting. Sterk sociaal-hiërarchische structuren belemmerden de communicatie met artsen, wat resulteerde in onvoldoende begrip bij ouders over de noodzaak om de therapie te continueren. De meeste arme patiënten konden zich de behandeling niet veroorloven. Toegang tot de gedoneerde cytostatica was niet adequaat. Dit resulteerde veelvuldig in het weigeren of stopzetten van de behandeling. Er was geen follow-up systeem

aanwezig om deze patiënten op te sporen en te contacteren. Ziekenhuispersoneelsleden waren zich er niet volledig van bewust dat hun eigen houding en communicatie-vaardigheden belangrijk waren voor het bevorderen van therapietrouw bij patiënten en ouders.

Gebaseerd op deze bevindingen is een gestructureerd voorlichtingsprogramma voor alle ouders ontworpen over leukemie, de behandeling, de gedoneerde medicijnen en de noodzaak tot het afmaken van de totale therapie. Sinds januari 2004 wordt dit voorlichtingsprogramma aan alle ouders gegeven. Het programma bevat: een video-presentatie in het ziekenhuis, een informatieboekje, audiocassette, DVD, procedure voor informed-consent, een contract voor de gedoneerde medicijnen en een klachten-procedure.

Hoofdstuk 1 illustreerde dat de behandelingsresultaten significant verschilden tussen arme en meer welvarende kinderen met leukemie in Indonesië. In **Hoofdstuk 2** bepaalden wij of de sociaal-economische status van ouders invloed heeft op de overtuigingen, de houding en het gedrag van ziekenhuispersoneelsleden die betrokken zijn bij de behandeling van kinderleukemie in Indonesië. Van november 2004 tot augustus 2005 vulden 102 ziekenhuispersoneelsleden (69 artsen, 28 verpleegkundigen, 2 psychologen, 2 laboranten, 1 secretaris) een semi-gestructureerde vragenlijst in. Wij vonden dat de meeste ziekenhuispersoneelsleden (98%) ouders vragen naar hun financiële situatie. De beslissing om te starten met de behandeling werd beïnvloed door de sociaal-economische status van de ouders (86%), motivatie van de ouders (80%) en motivatie van de artsen (76%). Ziekenhuispersoneelsleden verklaarden dat meer welvarende patiënten zich beter aan de therapievoorschriften houden (64%), dat artsen zich beter aan de therapievoorschriften houden bij meer welvarende patiënten (53%), dat de meeste patiënten zich het afronden van de behandeling niet kunnen veroorloven (58%), dat minder uitgebreide uitleg wordt gegeven aan arme families (60%), en dat communicatie wordt belemmerd door verschillen in status (67%). Een minderheid van de ziekenhuispersoneelsleden verklaarde dat zij meer aandacht schenken (27%), zorgvuldiger werken (24%), meer belangstelling tonen (23%), en meer tijd per bezoek besteden (22%) aan welgestelde families. De meeste ziekenhuispersoneelsleden ontkenden verschillen in de kwaliteit van medische zorg (93%) en de kansen op genezing (58%) tussen arme en meer welvarende patiënten. Wij concludeerden dat de overtuigingen, de houding en het gedrag van ziekenhuispersoneelsleden verschilden ten opzichte van arme versus meer welvarende patiënten. Deze verschillen dragen mogelijk bij aan het grote aantal drop-outs en de kleine kansen op overleving van arme leukemie patiënten in ontwikkelingslanden.

In hoofdstuk 1 beschreven we dat de toegang tot gedoneerde cytostatica van kinderen met ALL in Indonesië beperkt was tussen 1997 en 2004: slechts 16% van de families ontving donaties. Na de introductie van ons gestructureerde oudervoorlichtingsprogramma in januari 2004, onderzochten wij in **Hoofdstuk 3** de toegang van ouders van kinderen met ALL tot de gedoneerde cytostatica. Van de 72 nieuwe kinderleukemie patiënten die het ziekenhuis bezochten tussen november 2004 tot april 2006, werden 51 ouders (71%) geïnterviewd door onafhankelijke psychologen met behulp van semi-gestructureerde vragenlijsten. Ouders van 21 patiënten (29%) deden niet mee omdat hun kinderen therapie weigerden of voortijdig verlieten (n=10) of overleden waren (n=11) voordat een interview plaatsvond. Vier

ouders hadden een ziektekostenverzekering en de gedoneerde chemotherapie niet nodig. De toegang tot de gedoneerde chemotherapie was verbeterd: 46/47 patiënten (98%) ontving de donaties. Gestructureerde oudervoorlichting verbeterde de toegang tot de gedoneerde cytostatica. Deze benadering kan van nut zijn voor medische uitwisselingsprojecten tussen ontwikkelings- en meer ontwikkelde landen. Het kan meer arme patiënten in ontwikkelingslanden in staat stellen donaties te ontvangen en genezing te bereiken.

Het weigeren of voortijdig verlaten van de behandeling zijn veelvoorkomende redenen voor het falen van de therapie bij kinderleukemie in ontwikkelingslanden. In de meeste onderzoeken werden redenen voor het stoppen van de behandeling gebaseerd op de opinies van ziekenhuispersoneelsleden, weinig studies onderzochten de beweegredenen van de ouders zelf. Doelen van ons onderzoek in **Hoofdstuk 4** waren het in kaart brengen van de redenen van ouders om de therapie te stoppen en te achterhalen of de betrokken patiënten nog leefden of waren komen te overlijden. Wij verrichtten huisbezoeken om de families te interviewen van kinderen die tussen januari 2004 en augustus 2007 gediagnostiseerd waren met ALL en die de therapie hadden geweigerd of stopgezet. Gedurende deze periode waren 159 kinderen gediagnostiseerd met ALL van wie 40 kinderen (25%) de therapie hadden verlaten. Van deze kinderen werden 37 families (93%) thuis bezocht. De redenen voor het weigeren of voortijdig verlaten van de behandeling waren complex. De meeste ouders noemden verscheidene redenen. Financiële en transport moeilijkheden waren niet de enige of belangrijkste reden voor drop-out. Overtuigingen dat ALL niet te genezen is, ernstige bijwerkingen van de behandeling en ontevredenheid over ziekenhuispersoneelsleden waren ook belangrijke overwegingen. De meeste patiënten (64%) verlieten de therapie ten tijde van de diagnostiek of de inductie fase. Van de 37 patiënten die de therapie weigerden of verlieten, waren 26 (70%) kinderen overleden en 11 (30%) kinderen leefden nog, waarvan 2 kinderen meer dan 2 jaar na de drop-out. Wij concludeerden dat om het aantal patiënten dat de kinderleukemie therapie weigert of stopt te verlagen, niet alleen financiële en transport ondersteuning nodig is, maar ook oudervoorlichting, begeleiding, psychosociale hulp, verbetering van de kwaliteit van de zorg en adequaat behandelen van de bijwerkingen.

In **Hoofdstuk 5** onderzochten wij sociaal-economische, therapie-gerelateerde en psychologische ervaringen van ouders gedurende de ALL behandeling van hun kinderen. Kinderen werden behandeld met het WK-ALL-2000 protocol en ontvingen gedoneerde cytostatica. Van november 2004 tot april 2006 werden 51 ouders geïnterviewd door psychologen met behulp van semi-gestructureerde vragenlijsten. Het familie inkomen was gedaald (69%) sinds het begin van de behandeling. Ouders verloren hun baan (29% van de vaders, 8% van de moeders) en de meesten weten dit aan de leukemie van hun kind (87% van de vaders, 100% van de moeders). De kosten van de behandeling resulteerden in financiële moeilijkheden (78%), schulden (65%) en dwongen ouders om delen van de behandeling uit te stellen of hiervan af te zien (18%). Ouders verklaarden behoefte te hebben aan meer informatie (86%) van en contact (77%) met artsen. De oudervereniging bracht geen bezoek (69%) tijdens de ziekenhuisopnames en gaf geen informatie (59%) of emotionele steun (55%). Wij concludeerden dat de sociaal-economische impact van de leukemie behandeling aanzienlijk was. Communicatie tussen ouders en artsen zou verbeterd moeten worden. De rol van de oudervereniging was onbeduidend en vereist verbetering.

In **Hoofdstuk 6** vergeleken wij de resultaten van de kinderleukemie behandeling voor en na introductie van het gestructureerde oudervoorlichtingsprogramma. We bestudeerden de medische dossiers van 283 kinderen die gedurende 2 perioden waren gediagnostiseerd met ALL: voor (januari 1997-augustus 2002; n=164) en na (januari 2004-december 2006; n=119) introductie van het voorlichtingsprogramma. Gegevens over de behandelingsresultaten en de sociaal-economische status van ouders werden verzameld. Na introductie van het voorlichtingsprogramma, nam het aantal therapie weigeringen significant af en de incident-vrije overleving significant toe onder de arme patiënten. Het voortijdig verlaten van de behandeling nam toe onder de meer welvarende patiënten. In de totale patiëntenpopulatie nam de sterfte ten gevolge van toxiciteit significant toe en werd geen significant verschil in de incident-vrije overleving gevonden. Wij concludeerden dat na introductie van het voorlichtingsprogramma, arme families voor de eerste maal gestructureerde informatie ontvingen over leukemie, behandeling en gedoneerde cytostatica. Het weigeren van de behandeling nam significant af en de overleving nam significant toe onder de arme patiënten. Om de overleving van de totale patiëntenpopulatie significant te doen stijgen, is het belangrijk dat zowel de sterfte ten gevolge van toxiciteit als het voortijdig verlaten van de behandeling dalen. Verbetering van de kennis, vaardigheden en communicatie van artsen is hiervoor nodig. De intensiteit van de therapie moet worden afgestemd op de mogelijkheden van de supportive-care.

Hunger only for a taste of justice
Hunger only for a word of truth
because all that you have is your soul

Tracy Chapman

VI. GENERAL DISCUSSION

The aims of this study are:
1) To examine the influence of socio-economic status on childhood ALL treatment and treatment refusal or abandonment in a developing country.
2) To investigate parental experiences during childhood ALL treatment and their reasons to refuse or abandon treatment.
3) To determine whether a parental education program increases the access to donated chemotherapy and decreases treatment refusal or abandonment.

1) What is the influence of socio-economic status on childhood ALL treatment and treatment refusal or abandonment in a developing country?

Treatment refusal or abandonment was the main reason for treatment failure in children diagnosed with ALL between 1997 and 2002 in Yogyakarta, Indonesia. The differences in dropout rates between poor (47%) and prosperous (2%) patients and between children from parents with low, intermediate, or high education were sizable and statistically significant. Outcome of childhood ALL treatment could be improved substantially by interventions that help to prevent refusal or abandonment of therapy. Because most dropouts occur during the diagnostic process and the first weeks of treatment, any effort to reduce their magnitude should be implemented when patients first enter the clinic. This refusal and early abandonment of treatment can be expected to have a disproportionately adverse effect on survival, in comparison with abandonment in the later part of maintenance chemotherapy.
During 1997-2002 event-free survival differed significantly between poor (11%) and prosperous (45%) patients and significantly among patients with low, intermediate, or high parental education. In our study, income seemed a more important determinant than education.
Although the same protocol had been used, there was a striking disparity in the way treatment was provided to poor, as opposed to prosperous, patients. Only prosperous patients and their parents had 1 oncologist as a consistent caregiver throughout the whole treatment. The division between a VIP policlinic with oncologists for the prosperous and a general policlinic with residents changing over to other wards every month for the poor, implies that during the 2 years of outpatient care poor patients probably receive less time and attention from oncologists and thus less expertise. Yet most health-care providers denied that there is a difference in the quality of medical care between the poor and the prosperous and stated that they do not miss continuity in care at the policlinic for the poor. The awareness that individualized attention is essential for parents and patients and increases compliance and treatment outcome, needs to rise in developing countries too, because you cannot change what you do not acknowledge. Previous reports of successful strategies to reduce rates of therapy abandonment in children with cancer in resource-poor countries did not mention the need of poor families to receive individualized attention from oncologists too.
Poor survival rates of childhood ALL in developing countries may be attributed partly to poor communication between physicians and parents. Between 1997 and 2002 structured and complete parental education by physicians was lacking, particularly

among poor patients and their parents. Almost all health-care providers mentioned that they thought that parental education is crucial, yet most declared that they give less extensive explanations to poor families. Many providers were uncertain whether they are able to create a climate in which questions can be asked by parents and patients. Most health-care providers stated that their communication is hindered by differences in status and social hierarchical structures. Health care providers did not seem fully aware that their own attitude, their communication skills, their interest in the patient, knowledge, willingness to provide information, and their belief in the efficacy of treatment all were important and potentially are able to increase compliance of patients and parents.

The access to donated chemotherapy was insufficient between 1997 and 2002. In developing countries, it is important to verify whether donations reach those in need, by questioning not only the supervisors but also the recipients. Most poor families could not afford the extended and prolonged medical treatment. Lack of finances and insight into the necessity to complete the 2 years of treatment often resulted in refusal or abandonment of treatment. There was no follow-up system in place to ensure that patients with ALL attended their hospital appointments and to contact families in case of dropout.

We found that in a developing country, where until recently most patients had no health insurance, health-care providers were very much aware of the fact that money is a prerequisite to receiving medical care. Health-care providers wanted to know in advance about the financial position in which the families involved found themselves. They did not hesitate to ask parents about their finances. The decision to start or not to start treatment was influenced by the parental socio-economic status. We also learned that many health-care providers assumed that prosperous parents were more motivated to adhere to ALL treatment than poor parents and that many health-care providers expected doctors to comply better with the therapeutic regimen for the prosperous.

It is important for health-care providers to be aware of these perceptions as they may result in a self-fulfilling prophecy. If you expect people to perform less, your own input may decrease and subsequently the compliance of parents and patients may diminish and lesser performance and treatment results evolve.

We also learned that almost all health-care providers believed ALL is curable and most understood that the total treatment of 2 years needs to be completed. Yet at the same time many providers expected that most patients could not afford to complete treatment. Though the majority of health-care providers stated that the chance of cure is equal to all patients, still a considerable number admitted to their belief that more prosperous patients have a better chance of survival. As stated earlier, we found indeed that event-free survival was significantly higher in prosperous patients.

Health-care professionals need to realize that their own expectations and subsequent behavior differ between families with poor versus prosperous socio-economic backgrounds. This difference may play a role in the immense drop-out rate and slight chances of survival among less affluent patients. Awareness must grow that health-care providers themselves have an important influence on the compliance of parents and patients and thereby can influence treatment results and possible survival of children with ALL.

2) How do parents experience the childhood ALL treatment and what are the reasons of parents to decide to refuse or abandon treatment?

Starting from January 2004 a structured parental education program about leukemia, its therapy, availability of donated chemotherapy and compliance has been provided to all parents. After the start of this program parents whose children were treated for ALL or whose children had abandoned ALL treatment were interviewed.

Parents of children treated for ALL mentioned that they would like to receive more information about leukemia and its treatment. Strong social hierarchical structures frequently prevented parents from asking for more time and attention from doctors. Therefore it is important that doctors themselves should realize the need of parents for more contact and information. Knowledge and willingness of physicians to provide time, attention and information to parents and patients play significant roles in treatment compliance. Family-focused care is needed, in which families are acknowledged as an active part of the overall treatment. Survival partly depends on the behavior of physicians, parents and patients. Communication between parents and doctors ought to be improved.

We found that the role of the parent organization was insignificant and must be ameliorated. The majority of parents acknowledged the importance of the existence of a parent organization. Yet most parents stated that they had not received information, help or emotional support from the parent organization. Strong parent organizations are not easy to establish, particularly in developing countries. Serious, social hierarchical status differences between physicians and parents can hinder the functioning of parent organizations, and it is commonly not accepted that poor parents take on a leading role. As poverty is associated with little education, parents are frequently not capable of fulfilling leadership. Tensions and conflicts can arise when health-care providers and parent organizations have opposed interests. Such conflicts may be completely inappropriate in certain cultures, such as the Javanese. As parents depend on doctors for good care of their child, this may force them to be silent and raise no unrest. Therefore the methods of organizing parent groups must be adjusted to local cultures and needs. Doctors should learn that strong parent organizations are beneficial to the care of children with cancer, and promote their founding. All parties involved must understand that, once strong parent leaders operate and even if disagreements occur, this will eventually contribute to optimal patient care.

Most parents were optimistic about the curability of leukemia, although we found that between 1997 and 2002 in fact only 20% of patients survived. Most parents understood that fully 2 years of treatment are necessary and were positive about their ability to complete the 2 years of treatment. Only a minority did not expect to be able to complete the 2 years of treatment due to financial difficulties. This finding is in strong contrast to the health-care providers' perspective. The majority of health-care professionals expected most patients not to be able to complete treatment due to financial difficulties.

We learned that the socio-economic impact of the ALL treatment was profound, despite the availability of donated chemotherapy. Many parents became unemployed due to the illness of their child. Prolonged treatment-costs combined with decreased incomes caused most families to experience financial difficulties that resulted in debts.

In contrast to other studies, most parents declared that transportation difficulties were never reasons for missing hospital appointments, although travel time to hospital was >1 hour in 70%, and transportation considered expensive in 59%.

Parents were optimistic about their compliance with medication administration. Parents were positive about the quality of their relationship with their child, the openness of communication with their child, and about their ability to support their child emotionally. Parents also informed school of the disease openly, and felt no taboo on speaking about cancer.

Many parents considered the social support as provided by the village and the religious community, insufficient. This was all the more surprising because this society is known for its strong community feelings where the village, religion and family are concerned. Low social support has been associated with poor emotional health of parents and inadequate psychosocial adjustment.

Parents of children who abandoned treatment taught us that their reasons for abandonment were complex. Previous studies were based on expert opinions, yet we actually interviewed the families involved. Most parents mentioned several reasons. Financial and transportation difficulties were not the only, or even the main reasons, for abandonment. Belief of ALL incurability, experience of severe side-effects and dissatisfaction with health-care providers were also important considerations. Most patients (64%) abandoned treatment during the diagnostic-evaluation or remission-induction phase.

Some parents complained about the unprofessional attitudes of young residents who, for example, failed to perform lumbar punctures. Parents wondered whether these young doctors were allowed to practice on their child because they were poor. Performing lumbar punctures by less experienced doctors increases the risk of traumatic lumbar punctures. A traumatic lumbar puncture with lymphoblasts in the cerebrospinal fluid at diagnosis can adversely affect the treatment outcome of childhood ALL. It is therefore strongly recommended that lumbar punctures are performed by experienced physicians especially at diagnosis when higher numbers of lymphoblasts are circulating in the peripheral blood. In general, it should be considered that pediatric oncology cannot be done by rotating residents, even with good supervision. Children should be taken care of by a pediatric oncologist.

Health-beliefs about ALL curability in parents who refused treatment were based on “lay resources” such as stories or experiences of relatives, friends or other parents. Unfortunately, they went home immediately after diagnosis, before being exposed to the structured parental education program. In contrast, parents who abandoned treatment in later weeks initially believed and trusted the information given in the structured parental education program. However, after their child suffered from severe side-effects and having seen other ALL patients die after receiving chemotherapy they started to weigh the benefits and harms of chemotherapy. This insight has consequences for the prevention of treatment refusal and abandonment. For the refusers of therapy the structured parental education program should be initiated immediately after diagnosis, or better yet, while the diagnostic-evaluation is in progress. It is important to conduct non-patronizing, careful and open discussions when alternative medical treatment is proposed by parents or patients. For the parents who abandon therapy the structured parental education program should be an ongoing process, with regular group meetings of parents and professionals, to discuss their health-beliefs, fears, and experiences on the ward.

Side-effects also contributed to drop-out. Preventing and managing side-effects should therefore be emphasized. Health-care providers should have appropriate knowledge and skills to detect early and treat vigorously any complications that might arise. Supportive care for treating infections and hemorrhage, the most common causes of treatment-related death, should be improved. Adjusting the protocol based

on patients' observations is recommended in life-threatening conditions. It should be considered that most of our patients come from poor financial backgrounds and are malnourished. Poor nutritional status decreases tolerance of chemotherapy, is associated with altered metabolism of chemotherapy and increased infection rate, resulting in poor clinical outcome. Therefore, a simple situation-adjusted protocol based on local conditions is recommended.

Some abandonment decisions were made by patients themselves. Adolescent patients decided to stop treatment because they believed that chemotherapy cannot cure the disease and may even worsen their condition. Their belief seemed to be influenced by other similar-aged patients. They shared their experiences, feelings, and beliefs with their peer group. Some of their information came from overhearing the clinical round discussions. It is important that physicians do not discuss the patients' condition in front of the patient or other patients. Adolescents may pick up certain aspects of the information and may not be able to put it in the right context. This may create fear and misconceptions amongst them and their peers. Psychosocial support and open communication between health-care providers and a peer group of patients may facilitate their coping with the disease and its treatment.

Regarding their health-seeking behavior, we found that before abandonment most families complied with medical advice and did not visit traditional healers. However, after stopping the treatment they tried to find alternative treatments. In general, there were 2 reasons for using alternative treatment: 1) belief that alternative treatment was better than conventional treatment, and 2) a last effort, not to give up, to cure their children. The most common alternative method used was religious-spiritual. It correlated with their belief that suffering from ALL was destined, the will of God/Allah. The families believed that a religious method would at least improve the child's quality-of-life and that of their family members.

We concluded that reducing treatment abandonment of childhood ALL in developing countries requires not only financial and transportation support, but also parental education, counselling, psychosocial assistence, improvement of quality-of-care and adequate management of side-effects.

3) Does the structured parental education program increase the access to donated chemotherapy and decrease treatment refusal or abandonment?

Before introduction of the structured parental education program, information about leukemia, treatment and availability of external funding was seldom given to poor families. Residents provided parental education for the poor. However, residents lacked experience in pediatric-oncology and knowledge about funds; consequently, information was not complete. Strong social hierarchical structures hindered communication between doctors and poor parents. As a result, many parents did not understand why it was important for children to take their medication daily during 2 years. Most parents could not afford prolonged treatment costs and had no access to donated chemotherapy. Not all health-care providers believed it possible to cure poor patients with leukemia, which requires an expensive, prolonged treatment. Most health-care providers believed that prosperous patients complied better with treatment and that doctors comply better with treatment for prosperous patients. We warned for a self-fulfilling prophecy. If doctors expect poor families to perform less, their own input may decrease and subsequently compliance of parents and patients may

diminish and lesser performance and treatment results evolve. Starting from January 2004, a parental education program for all parents, poor and prosperous, was introduced to increase access of poor patients to information about leukemia, treatment and donated chemotherapy. The program contained: a video-presentation in hospital, information booklet, audiocassette, DVD, procedures for informed-consent, statement of understanding for donated chemotherapy and a complaints-mechanism.

We found that structured parental education in an Indonesian academic hospital improved access to donated chemotherapy: we assessed 71% of parents in our sample, and found that 98% of patients received donations, as opposed to 16% in the past. Poor and prosperous parents were informed about leukemia, its treatment and chemotherapeutic drugs available through donations. No significant differences existed between poor and prosperous parents in receiving various parts of the education program. We also learned that extra attention must be given to informed-consent, which most parents signed, yet did not understand.

We found that doctors working at the hematology-oncology department often failed to explain diagnosis and treatment to poor families. In Indonesia children are assigned by socio-economic status to different levels of medical care. However, also poor children need an oncologist, not just a rotating junior resident, taking care of them throughout the treatment. Awareness must grow that communication with all families, poor and prosperous, is essential. Doctors themselves have an important influence on compliance of parents and patients, and hereby can influence treatment results and possible survival of children with ALL.

We learned that not only an education program for parents, but also an education program for health-care providers is required. This program should not only aim at improving knowledge and skills of doctors, but it must also raise awareness about the significant impact that interest in poor and prosperous patients can have. Willingness to provide information to all parents and patients, checking whether information has been understood and training of proper communication skills are of the utmost importance.

Before the introduction of the parental education program, health-care providers charged for the donated chemotherapy. This cannot be accepted. Aid agencies must improve the quality of their accountability to beneficiaries because if beneficiaries know what they are to receive, beneficiaries can complain if aid is not given. Criteria and procedures for assigning assistance should be clear, simple and transparent. Complexity makes it difficult for beneficiaries to call aid organisations and doctors to account because criteria cannot be comprehended and retained. Health-care providers should not select beneficiaries themselves.

It is important that participants of outreach-programs examine and understand the nature of power in indigent societies, where commonly strong social hierarchical structures exist. Vulnerability of the poor should be understood in terms of powerlessness rather than simply lacking basic means. Power and powerlessness determine access to aid. Those who lack power cannot safeguard their rights. Aid may be used by the strong to neglect, exclude or exploit the powerless. Supervision by aid agencies should therefore be improved. Monitoring and reporting are critical tools for accountability, but can also be used to conceal evidence of inappropriate use of donations. The extent to which reporting processes can be checked is restricted. Access may be limited, and agencies may make only occasional visits. The same personnel is frequently responsible for both implementing and monitoring a project. This makes it almost impossible to track improper use of donations. Also after

installation of complaints-mechanisms, the extent to which beneficiaries are truly independent and able to complain without fear of losing aid is limited.

It is important to increase access to aid in outreach-programs through: 1) installation of clear and simple criteria and procedures to receive aid; 2) education of beneficiaries about their rights to receive aid; and 3) checking through interviews with beneficiaries by independent investigators whether donations are properly given. This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure.

After introduction of the structured parental education program, treatment refusal decreased significantly and event-free survival improved significantly in poor children. This illustrates that showing interest, investing time, willingness to provide information, and giving donated chemotherapy to poor families are potentially able to increase compliance and improve survival of poor patients.

Because prosperous patients already had access to information about ALL from their personal oncologists and could afford the required chemotherapy before introduction of the education program, we did not expect their treatment outcome to differ much after introduction of the program. However, we did find that prosperous patients abandoned treatment more frequently. To understand this increase some background information is required: After institution of limited health-insurance in 2005, oncologists intensified treatment. Therefore toxicity also increased. From interviews with dropped-out families we learned that prosperous patients abandoned treatment due to fear of toxicity. After seeing severe side-effects in their child or other children die on wards after having received chemotherapy, parents decided to stop treatment.

Treatment-related death increased significantly in the overall population. Several factors may have contributed: 1) Now that less patients drop-out more patients are at risk to die of treatment-related toxicity. 2) Use of intensified and more toxic chemotherapy leads to increased chance of toxic-death, if supportive-care facilities do not keep pace with this intensification. Most patients are poor and malnourished. Poor nutritional status decreases tolerance of chemotherapy, alters metabolism of chemotherapy, and is associated with increased infection-rate, resulting in poor clinical outcome. Protocol adjustments based on patients' observations are recommended in life-threatening conditions. Doctors must improve their knowledge and skills to detect and vigorously treat complications, as early as possible. Health-care providers need an education program about handling treatment toxicity. Intensity of treatment should be matched with possibilities of supportive-care. 3) Recent increase in hospital admittances. Long waiting-lists for hospitalization resulted in delays in leukemia treatment administration according to protocol. Immune-compromised leukemia patients in overcrowded hospital rooms were more at risk to develop potentially fatal infections.

Although treatment refusal in the poor and overall population decreased significantly, the problem remains that substantial numbers of poor and prosperous patients refuse or abandon treatment. From the families who refused treatment, we learned that education programs should be initiated during diagnostic evaluation. From the families who abandoned treatment, we learned that education programs should be an ongoing process, with regular group meetings of parents and professionals, to discuss health beliefs, fears, and experiences on wards.

Historical analyses have weaknesses. Without some control or randomization, they cannot really demonstrate that results are only due to the intervention. This weakness applies to our parental education program about leukemia and the donations too. Also the small number of prosperous patients limits the interpretation of our results.

We conclude that after introduction of the parental education program poor families received structured information about leukemia, treatment and donated chemotherapy for the first time. Treatment refusal decreased and survival increased significantly of poor patients. However, work remains to be done. To improve survival, it is important that toxic-death and treatment abandonment decrease as causes of treatment-failure. Improvement of knowledge, skills and communication of health-care providers is required to manage treatment toxicity and prevent treatment abandonment. Treatment intensity should be matched with possibilities of supportive-care.

Our lives begin to end
the day we become silent
about things that really matter

Martin Luther King

VII. RECOMMENDATIONS

On the basis of the findings in our studies, we provide the following recommendations for better survival of childhood ALL patients:

1) Pediatric oncology centers in developing countries should provide not only prosperous but also poor patients with 1 oncologist as a consistent caregiver during the course of treatment.

2) A structured parental education program should be provided as an integral part of care and it should be first provided at diagnosis and thereafter continuously repeated during the treatment. The program should contain information about leukemia, its therapy, the necessity to complete treatment, and the availability of funds to prosperous, as well as poor, patients and parents.

3) Hospitals need a follow-up system for detecting and contacting promptly families who miss hospital appointments.

4) It is important to increase access to aid in outreach-programs through:
a) installation of clear and simple criteria and procedures to receive aid;
b) education of beneficiaries about their rights to receive aid;
and c) checking through interviews with beneficiaries by independent investigators whether donations are properly given.
This may enable more patients from poor socio-economic backgrounds in the developing countries to receive aid and achieve cure.

5) An education program for health-care providers is required. This program should:
a) improve knowledge and skills about how to apply treatment according to the protocol and handle treatment toxicity;
b) contain training of proper communication skills and emphasize the significant impact that showing interest, providing information, and checking whether information has been understood can have.

6) Since the majority of ALL patients are treated by residents, better teaching and supervision of residents are necessary to improve their knowledge, skills, attitudes and communication with childhood ALL patients and their families.

7) Prevention and adequate management of side-effects is needed to ameliorate the quality of life of patients and prevent treatment abandonment.

8) Improvement of supportive care is needed to prevent toxic-death.

9) Intensity of treatment should be matched with local circumstances (e.g. malnutrition, infections) and possibilities of supportive care. Use of a simple situation-adjusted protol is recommended.

10) Lumbar punctures and bone marrow punctures should be performed by skilled health-care providers (pediatric oncologists).

11) Psycho-social support for parents and patients should be provided.

12) Medication availability should be guaranteed.

13) Hospital room availability should be guaranteed.

14) Government insurance should be continuous and include all chemotherapy and supportive treatment.

15) The role of the parent organization must be ameliorated. Doctors should learn that strong parent organizations are beneficial to the care of children with cancer, and promote their founding and functioning.

These measures most likely will have a positive influence on patient compliance and on outcome of treatment.

Addendum:

SOME CULTURAL BACKGROUNDS

To deny the past
is to forget the future

I. A HISTORY OF INDONESIA

Hereby I would like to point out that the following historical reconstruction of what is nowadays known as "the Republic of Indonesia" focuses mainly on Java. Keep in mind that any resume of the past does not describe the actual historical reality, but just gives an image of it.

I.1 INDONESIAN EMPIRES (1300-1650)

I.1.1 MAJOR EMPIRES

Although there is not much evidence of historical events in Indonesia, we know that during the 14th and 15th century two major empires co-existed: the Hindu-Buddhist state Majahapit in East-Java and the Islamic state Malacca in Malaya (currently known as Malaysia). Both wealthy empires were famous for their national and international trade. They had the largest commercial system of the world with connections to India, Persia, Arabia, East Africa, the Mediterranean and China. Their most significant trade products included spices, rice, textiles and slaves. Majahapit possessed land on which products were cultivated, whereas Malacca owned a very successful port where the wealth of Asia was exchanged.

The interior of Java was divided by volcanoes, mountains and highlands into isolated regions that could often only be reached by rivers. Java was underpopulated and large pieces of land were not inhabited at all. The populated territories possessed the richest rice lands in the world.

Due to their dispersed locations and poor accessibility, these isolated regions could not be ruled by a single strong king or emperor alone. Therefore a restricted kingdom was created in which the king gave a great amount of autonomy to regional lords and princes. This created breakable empires with tensions between regional and central authorities. The king tried to preserve his power by rendering the regional leaders and princes autonomy, wealth, status and protection in return for their support. Political marriages were arranged and spies installed. Aside from this, the king created a glorious supernatural cult about himself and his court. Yet most important was the establishment of a superior military that could destroy any opposition (1).

I.1.2 ISLAMISATION

The spread of Islam has been an important feature of Indonesia's history and a continuous process down to the present.

Islamisation of Indonesia has been a slow phenomenon. Muslim traders had already been present in Indonesia for several centuries, when the first important Indonesian conversions to Islam occurred during the 13th and especially the 14th and 15th century.

Islamisation occurred in two ways. First, indigenous Indonesians came into contact with Islam and conversed to this faith. Ordinary citizens encountered Islam mainly

through Muslim traders. At courts the royals were influenced by Islam through Muslim mystics and holy men. Second, Muslim immigrants married Indonesians, had offspring and integrated into Indonesian society.

Many Javanese Muslims, including the royal families, held and still hold on to their Hindu-Buddhist beliefs as well. This does not mean that the Islamisation process in Java is superficial. Islam altered several important Javanese customs. *For instance, circumcision and burial were introduced.* Also the rich Hindu-Buddhist cultural heritage is still preserved in currently Islamised Java. *Let us give a few examples. The Javanese shadow-puppet theater, called wayang, is based on Hindu stories. Dance, performed in pre-Islamic courts and depicted on ancient Javanese Hindu temples, is still popular. Java was the center of gong music in pre-Islamic times. Gongs are still used in the Javanese "gamelan" orchestra. Javanese believe the instruments have spiritual personalities and bring them offerings. Not only wayang puppets, classical music and dances, but also krises (daggers) and batik (dyed fabric) are considered sacral in nature. They are believed to contain supernatural forces and energies. Also nowadays Indonesian arts can only be employed with extensive rituals and rules.*

In general, wars in Java were not to spread Islam. However, once an area was conquered by Muslims, Islam spread here subsequently (1).

I.1.3 ARRIVAL OF EUROPEANS

During the 16th century the first Europeans arrived in Indonesia. In this century European impact on the archipelago was restricted. They possessed no meaningful power and no land in this region.

At this time Europe was neither the most sophisticated nor the most powerful region in the world. In contrast, the Islamic world however was very powerful and conquering large territories: at the western border it spread in Constantinople and at the eastern border in Indonesia.

The Europeans, particularly the Portuguese, improved their technological knowledge what led to better ships with artillery. Mainly Arab teachings enlarged their know-how of geography and astronomy. This enabled them to become better navigators. The Portuguese desired to expand their territory overseas for several reasons. Besides from the glory, they wanted to look for gold, spices and a way to become less dependent of their Arab enemy. Spices were essential to preserve meat and Arabs monopolised the spice trade. Europeans were incapable to keep large herds of animals alive during the cold winters and therefore needed spices for preservation. Besides this spices were also appreciated for their taste. The Arab merchants mentioned that the spices came from the "Spice Islands" of Indonesia and although the Portuguese had no idea where these isles were situated, they were determined to find them.

The Portuguese king ordered to set sail for Malacca and the Spice Islands of Indonesia. Initially the plan was to make a friendly deal with the residing ruler. But the Portuguese soon realised that their goods, which they hoped to sell for Asian products, were useless in the advanced Asian trade**.** In 1509 the first Portuguese ships arrived in Malacca, where they encountered hostility from the ruling sultan. Portuguese sailors and adventurers were captured and killed and their ships assaulted.

The Portuguese thereafter concluded that conquest and establishment of permanent bases was the only way to profit from Asian trade.

In 1511 Malacca was conquered by the Portuguese. They were however not able to control or monopolise the Asian trade. Many Asian merchants simply moved their trade to other ports and Malacca lost its significance as a central trading port. Hereby the sophisticated Asian trade network was disrupted. The Portuguese also faced many other difficulties. They were dependent upon Asian food supplies and lacked finances and manpower. Their organisation was characterised by inefficiency and corruption. Soon the Portuguese lost their interest in Indonesia. Long after their conquest stopped, a few devoted Portuguese catholic priests founded some Christian communities in East Indonesia. Besides this and some Portuguese vocabulary and family names, Portuguese influence on the Indonesian culture was limited.

The Dutch arrived in Indonesia after the Portuguese. The Dutch were in desperate need to expand overseas. They were in war against Spain and when Portugal and Spain united, their access to Asian spices via the Portuguese stopped. This enhanced their will to get the Indonesian spices themselves. In 1596 the first Dutch expedition arrived in Java. The Dutch organisation, ships, guns and finances were better than the Portuguese. The seamen from the Netherlands raised conflicts at every port they visited with both Indonesians and Portuguese. A competition among different Dutch shippers emerged. As a result Dutch sailors had to pay higher prices for the spices in Indonesia, whereas the increased import of spices in Europe decreased their profits. On request of the Dutch parliament the competing companies united and established the “United East India Company” or “VOC” (Vereenigde Oost-Indische Compagnie) in 1602. The Dutch parliament allowed the VOC to build fortresses and conclude treaties in Asia. Though the VOC was Dutch, many of its personnel was not. European adventurers, criminals and poor joined. The VOC personnel was known for its inefficiency, dishonesty, nepotism and alcoholism.

The Dutch initially met competition from the Portuguese and later the British. After a while Portugal and England lost interest in the spices of Indonesia and sought their products elsewhere.

When Jan Pieterszoon Coen became Governor-General of the VOC in 1619, its policy harshened. Coen wanted to gain power by force, war and destruction of everything that got in the way of the VOC. The locals were not able to fight against the powerful navy of the VOC. The only possible resistance seemed smuggling of trade products. Dutch attempts to stop the smuggling consisted of deporting, killing or starving to death of whole populations.

The Dutch looked for a safe port in Indonesia where they could create a permanent base for their warehouses and navy. Coen choose the town Jayakerta with its great harbour. *Jayakerta was at that time ruled by a Muslim prince and belonged to the central king in Banten. The latter had used the British to get rid of the Dutch. Thereafter Bantenese troops repelled the British and occupied the city. However the Dutch returned and conquered Jayakerta in 1619.* The Dutch burned the city to ashes and renamed it Batavia. The new VOC headquarter was solely under Dutch control and had no nearby Indonesian empires that could pose a threat. Batavia formed the base from which the Dutch were later to expand their power. But Batavia also caused

tremendous financial difficulties for the VOC. The town had to be built and defended. Mainly Indonesians and Chinese, all attracted by commercial opportunities, inhabited Batavia. The population depended on import of food supplies. Timber had to be imported too for the construction of ships and houses. This forced the Dutch to get involved with the different Javanese kingdoms. These Javanese courts were characterized by intrigues. All led to tremendous expenses by the VOC (1).

I.1.4 NEW ISLAMIC EMPIRES

During the arrival of the first Europeans in the 16th century, new Islamic empires were being installed. Unfortunately their history is not adequately documented. Also in this era successful empires were ruled by strong central rulers in possession of powerful armies. The ruler rendered favours to the elite in order to keep them satisfied and receive their support. We will highlight the situation in Java to give an impression.

In Java the Hindu-Buddhist state Majahapit collapsed and new Islamic states arose. The three most important were Mataram in the center of Java and Surabaya and Banten at respectively the eastern and western coast of Java. This time was characterized by a bitter warfare between the coastal and interior courts. During the 16th century coastal regions dominated the center of Java, but under the Mataram rule of sultan Agung this changed in the 17th century.

Sultan Agung

The predecessors of sultan Agung started the expansion of the Mataram empire with the use of a strong military. When sultan Agung succeeded his father in 1613, he became the greatest warrior king of Indonesia. During his reign he conquered almost all of Java. He used brutal military force and destructed the coastal regions along with any kind of opposition. Populations were deported. Many people died during battles. His wars disrupted agriculture what resulted in the starvation of many Indonesians. Sultan Agung saw himself as invincible and wanted to prove this over and over again. Mataram was one of the most powerful Indonesian empires of the time. Mataram became the political center and created the most powerful and most longlasting Javanese kingdom. In fact the court is still alive today.

The father of sultan Agung had made the first contacts with the VOC to ask for an alliance. He had hereby hoped the VOC would support his war against the state Surabaya. However after the alliance was established, the Dutch set up trading posts in both Mataram as well as in Surabaya. The VOC operated in both kingdoms under control of the Indonesian sultans.

Sultan Agung himself had a difficult relation with the VOC. The VOC was interested in a friendship with Agung in order to buy rice from his land. But the rice cultivation was disrupted by Agung's wars and the sultan forbade to sell rice to the Dutch. Sultan Agung warned the VOC never to conquer any land in Java. When the Dutch eventually did occupy Batavia an army was sent by the sultan to destroy the VOC. Agung's army was however defeated. It was the only defeat Agung had during his rule. First Agung concluded an alliance with the Portuguese against the VOC, but when he realized that the Portuguese were not able to withstand the Dutch, he ended this cooperation. Agung found it more important to invest in his wars with his

indigenous enemies and therefore tried to establish more friendly relations with the Dutch again.

More than the coastal courts, the Mataram court held on to many Hindu and Buddhist beliefs and customs. *For instance, the Mataram kings looked and still look for protection from the Goddess of the Indian Ocean. This Goddess is supposed to be a princess who was expelled from the court when she refused an arranged marriage. The Goddess now lives in a palace in the ocean. Every year the royal family still brings offerings to the ocean at Parangtritis, a beach near Yogyakarta.*

Sultan Agung was the first Mataram king who fully embraced Islam. *Let us give some examples. Agung went on a pilgrimmage and introduced the Islamic calendar. Agung constructed a grave-site on the top of a hill at Imagiri. Most of his successors are also buried here and it is still respected as a sacred site.* When sultan Agung passed away in 1646 he was and nowadays still is regarded as a holy man (1).

I.2 CONTESTS FOR POWER (1630-1800)

I.2.1 DISINTEGRATION OF STATES

The 17th and 18th century were characterized by disintegration of the different states. Though warfare was always part of Javanese history, the nature of it changed. Indonesia started to get more involved in the global economy. The international demand for new products brought prosperity to local rulers and undermined the authority of central kings. This frequently led to rebellion and disintegration of states.

As the demand for Indonesian products increased, more labourers were required. This enlarged the market of slaves from mainly the outer Indonesian islands. Indonesian kings grew rich by selling their criminals, debtors and prisoners of war as slaves.

The VOC owned no valuable trade products that they could exchange for Indonesian products, but they did possess the most powerful navy in Indonesia. Therefore the VOC concluded treaties in which they gave military and political protection to kings in return for trade. Usually these treaties were just a piece of paper, which Indonesian kings used or ignored whenever they wanted. This eventually contributed to the bankrupty of the VOC.

<u>King Amangkurat I</u>
After the death of sultan Agung in 1646, his son Amangkurat I became the new king of Mataram. Amangkurat I was known as a tyran who wanted to centralise the empire's finances and bypass the local rulers. But this was not possible due to the widespread isolated regions that belonged to his kingdom. Amangkurat I killed all he thought opposed him, including his own family, family in law and many local rulers. This caused fear and the longing for independence in other powerful men. Eventually this led to a great rebellion and VOC interference.

Amangkurat I started in a friendly relation with the VOC. The king interpreted their treaty as a submission of the Dutch to his rule. The VOC was interested in Mataram for the rice and timber that it produced in the coastal regions of the empire. The king

wanted to prevent that the local rulers got wealthier from this trade and forbade the export of rice and timber. He informed the Dutch that they could only negotiate with him about the amount and price of the products. In this way he hoped to collect all the profits himself. When this plan did not succeed, the king ordered the closure of all the ports. Even local fishermen were not allowed to fish anymore. Amangkurat I rather destroyed the coast than see others grow rich from it.

Meanwhile the opposition grew stronger. The king believed his eldest son Amangkurat II to be a threat to his position and tried in vain to poison him. This crown prince grew up with his mother's family, of whom most were murdered by his father. It created a profound dislike of his father in Amangkurat II. The crown prince got involved with prince Trunaya of Madura. Trunaya hated the king, as the king had killed his father. The crown prince and prince Trunaya planned a conspiracy and rebellion against the king. They agreed that after the defeat of the king, Amangkurat II would become the new king. Trunaya led the rebellions. Many local rulers and Javanese joined their fight.

Javanese believed that each court falls at the end of the century. The end of the 17th century approached and other predictive signs were seen: the volcanoe Mount Merapi erupted, earthquakes occurred, rain fell in the dry season and famine and epidemics were widespread. This might have inspired many Javanese to fight against a court of which they thought the end was already in sight.

Both the crown prince and Trunaya asked the VOC for military equipment, but the VOC refused. The Dutch wanted stability in Mataram to ensure the continuance of rice and timber cultivation. The VOC believed that only support of the king could bring this stability.

In general the VOC was ignorant of the intrigues in Indonesian courts and simply assumed that the king had a right to the crown by birth. The Dutch did not understand that in Java not only birth, but also perceived ability by local rulers and princes, determined whether one had a legitimate right to the throne. Frequently the VOC supported kings of whom the Javanese notables were convinced they had no right to rule. Hereby the VOC enlarged the instability and disintegration of states.

So the VOC supported king Amangkurat I with military forces which only increased instability. While his people wanted to get rid of Amangkurat I, the support of the VOC ensured his reign.

Finally Trunaya's forces conquered the court and during his flight the king died in 1677. Trunaya now claimed the crown himself instead of rendering it to the crown prince.

<u>King Amangkurat II</u>
In 1677 the VOC concluded a treaty with the crown prince Amangkurat II, in spite of the tremendous debt the Mataram court already had with the VOC. The Dutch marched into Mataram and defeated Trunaya's troops. In 1680 Trunaya was personally stabbed to death by the new king Amangkurat II.

From now on there was a clear relation between the VOC and the Mataram empire. The VOC had invested a large amount of money and military troops in Mataram and expected to receive profits from this investment. For the Mataram kingdom other issues became important, but from now on they could expect VOC interventions in their politics.

At start king Amangkurat II tried hard to repay the VOC. But as time passed ,in which rebels were eliminated and peace returned, the king became more confident and less willing to act according to the rules of the treaty with the VOC. Thus payments of the king to the VOC were not made and rice, timber and sugar were not provided. A conflict arose between the Mataram court and the VOC.

Meanwhile the VOC faced many internal problems. Governor-General Speelman abused his power and was very corrupt. *He arrested and convicted innocent men, sold free persons as slaves, received payments for non-existent soldiers, underpaid his Indonesian suppliers and operated without consent of the employers in the Netherlands.* VOC personnel were in general known for their corruption, alcoholism and brutality toward the Indonesians. The Dutch became increasingly disliked. Life for VOC employees was hard: most died young as a result of war, local disputes, alcoholism or diseases.

King Amangkurat II offered refuge to Surapati, a former Balinese slave who escaped slavery in Batavia. Surapati became a leader of a rebellious group and an enemy of the VOC. Surapati atacked and killed VOC personnel. The king strongly disliked the new Governor-General Tack who had instructions from the Netherlands to collect money from the king. The king and Surapati planned an assault on Tack and the VOC. When Tack paid a visit to the court, he was killed by Surapati and Javanese troops disguised as Balinese. This deteriorated the relation with the VOC. The king soon found out that it had been a mistake to protect Surapati as the latter started to conquer Mataram territories.

The empire of the king fell apart. Territories were taken in by different actors: his son and crown prince Amangkurat III, his cousin and prince Pakubuwana I, Surapati and the powerful lord of Madura Cakraningrat II. After the death of the king in 1703 his son succeeded him (1).

I.2.2 WARS OF SUCCESSION

King Amangkurat III

The new king Amangkurat III had friendly contacts with Surapati. Prince Pakubuwana I fled from the court and asked military support from the VOC. *The VOC saw a reliable ally in lord Cakraningrat II from Madura. This Madurese lord informed the VOC that prince Pakubuwana I had the support of the Javanese.* Here upon the VOC decided to support prince Pakubuwana I. It led to the First Javanese War of Succession (1704-1708). The VOC intervention was costly and many men lost their lives. Ultimately Surapati was murdered and king Amangkurat III got arrested and died during exile.

King Pakubuwana I

Pakubuwana I became the new king, but his Javanese support appeared not to be as strong as the VOC was told. The new treaty arranged a firm position for the VOC in Java. King Pakubuwana I made a serious effort to pay the VOC. He ordered local rulers to fulfil their payments. As a result labourers left the rice fields and moved to other regions. Large areas had already been deforested. Subsequently the VOC could not receive sufficient rice and timber supplies as was agreed. Local rulers resented the king who demanded payments. Resistance and rebellion grew. The VOC had to suppress this opposition. Again VOC policy resulted in more expenses instead of profits, and state disintegration instead of stability.

King Amangkurat IV

When king Pakubuwana I died in 1719, his eldest son Amangkurat IV became the next king**.** King Amangkurat IV had no support from the aristocratic or ordinary Javanese. His younger brothers led an assault on the king with support of Islamic leaders. Again the VOC assisted the king and thus the Second Javanese War of Succession (1719-1723) began. The rebel princes were defeated. The king, after his position was secured, deliberately frustrated, used and misled the Dutch.

The VOC got irritated by the meaningless Indonesian promises of trade and payments. The Dutch realised they got too involved in court intrigues, in which notables sought power and prosperity.

King Pakubuwana II

After the death of king Amangkurat IV in 1726, his son became king Pakubuwana II.

The situation at Batavia exacerbated. The constructed fishponds led to deadly malaria epidemics. The VOC administration was characterized by conflicts and tremendous financial losses. The Europeans felt unsafe in Batavia. The VOC discovered a plot to murder Europeans by Muslims and executed the suspects. Tensions arose from the large number of Chinese in Batavia. Chinese traders had been present for centuries in Indonesia. They were disliked and envied. Despite the brutal and corrupt treatment the Chinese received and a VOC attempt to stop immigration, their numbers increased. Due to this, unemployment among Chinese rose and many joined criminal activities. In 1740 the VOC suspected that the Chinese planned an assault. When Chinese gangs killed Europeans outside the city, the VOC feared the Chinese community inside Batavia would join. The VOC installed a curfew in the Chinese quarter and searched for weapons in Chinese houses. Soon the situation got out of hand and a terrible massacre emerged in which approximately 10,000 Chinese were murdered by Europeans and slaves. Those Chinese who managed to escape the slaughter, jointly attacked VOC posts and killed their inhabitants.

King Pakubuwana II joined the Chinese in their fight against the Dutch. Cakraningrat IV and his Madurese troops assisted the Dutch and conquered East Java. The fighting lasted for 17 years. The Chinese got defeated and the Mataram empire fell apart. Finally king Pakubuwana II begged the VOC for forgiveness and the latter gave in. Now thousands of Javanese, who had joined the anti-VOC war, felt betrayed by the king. Rebellion against the VOC and Pakubuwana II resulted. Different important princes supported the rebels. But thanks to a new treaty with the VOC and their military troops, the king could stay on his throne.

King Pakubuwana II remained on the throne, yet still faced rebellious princes. The king promised a large reward to the person who could drive the rebels away. Mangkubumi succeeded to do so. The VOC Governor-General proposed to king Pakubuwana II to lease the coastal regions of the Mataram empire to the VOC. The VOC expected to gain profits from this deal, but told the king that it was a solution for his problems to rule in this area. The king agreed. The Dutch advised the king not to render Mangkubumi the reward as this would make him too powerful. When Mangkubumi heard that the coast was rented to the VOC and he was denied his reward, he went into rebellion and the Third Javanese War of Succession (1746-1757) began. The VOC assisted the king, but this time the VOC troops were impoverished and not able to win the war. The king got ill and declared that the VOC could have his kingdom (1).

I.2.3 PARTITION OF MATARAM DYNASTY

King Pakubuwana III and sultan Hamengkubuwana I

The VOC did not want to reign the state and announced the crown prince Pakubuwana III to be the new king in 1749. However at the same time followers of Mangkubumi announced him to be the new king. Mangkubumi renamed himself king Hamengkubuwana I. Again the Mataram empire faced a war between a rebel king and an official king assisted by the VOC. This time though the rebellion was too strong to be defeated and the VOC too weak to conquer. Subsequently nobody won. The VOC decided to start negotiations as it could not afford the war expenses anymore. In 1754 the VOC intervention resulted in a partition of the Mataram kingdom in two states. Pakubuwana III received the Surakarta court and Hamengkubuwana I erected a court in Yogyakarta.

Peace returned and after centuries of warfare in Java, the elite decided that preservation of peace was a desired good in itself. Agriculture flourished. Problems remained, but now were restricted to the separate courts. Stability and peace lasted for a relatively long time.

As stability was accomplished, the necessity of courts to cooperate with the VOC declined. The VOC was in bad shape. An internal investigation showed mismanagement, corruption and bankruptcy.

Hamengkubuwana I of the Yogyakarta kingdom became the greatest ruler of the Mataram dynasty since sultan Agung. After Agung he was also the first to receive the title sultan. Under his reign the Yogyakarta kingdom grew more rich, stable, and powerful. The Yogyakarta court had the strongest military force in Java. Many Javanese prospered and the rapid growth of the population set in.

On the contrary, king Pakubuwana III of the Surakarta kingdom could be described as an incompetent ruler. His reign was characterized by court intrigues, decrease of stability and malbehavior of the Dutch officials.

The Mataram kingdom had been divided in 1754, yet this was never officially concluded. Meanwhile the end of the century came closer. Javanese believed that old courts fall and new ones arise at the end of centuries. This troubled the Yogyakarta

and Surakarta courts. They wanted to secure their position as new kingdoms in the 19th century. Therefore an official statement was made in the 1770s. It declared the permanent fall of the Mataram empire and the emergence of the Surakarta and Yogyakarta courts. Hereby continuance of their existence was safe-guarded.

The partition of the Mataram dynasty had on the one hand brought stability to Java, yet on the other hand made it also impossible to resist the European threat together (1).

I.3 COLONIALISM (1800-1910)

I.3.1 NAPOLEON

Napoleon conquered the Netherlands in 1795 and the VOC was declared property of the Dutch government. In Indonesia this had few consequences for the VOC as the same employees constituted the company. It did however change the relation between the Europeans and Javanese. The new spirit of anti-feudalism altered the European attitude toward the Indonesian aristocrats. For the first time the VOC claimed sovereignty in Java.

Sultan Hamengkubuwana II and king Pakubuwana IV

After the death of his father in 1792, sultan Hamengkubuwana II of Yogyakarta threatened the stability, prosperity and strong military of his kingdom. He wanted to decrease the influence of the elite. In the past every Javanese king had ruled with consensus of the aristocrats. Hamengkubuwana II however bypassed the elite. The sultan replaced his father's advicers and installed less talented acquintances. He created a more oppressive tax system that primarily formed a great burden on the outer regions of his sultanate. The relations with the VOC worsened. The influence of his three wives and thereby the court intrigues enlarged. In Java all of this led to a stronger opposition against his reign.

King Pakubuwana IV of Surakarta detested the partition of the Mataram dynasty and the Yogyakarta kingdom. Pakubuwana IV tried to turn the VOC against sultan Hamengkubuwana II.

When the Dutch king William V fled from Napoleon to England in 1795, he ordered the VOC to surrender to the British in order not to lose their Indonesian territories to the French. Napoleon sent Governor-General Daendels to resist the British in Java.

In 1808 the relation between Europeans and Javanese altered. Daendels wanted to reform the VOC administration and get rid of its corruption, abuse of power and inefficiency. Daendels' anti-feudal convictions resulted in reduced incomes and power of aristocrats. For the first time the VOC tried to rule in the interior of Java.

In contrast to Pakubuwana IV, Hamengkubuwana II did not accept the changed Dutch attitude. Conflicts arose. Daendels recruited mainly Indonesians for the Dutch military. In 1810 the sultan and Yogyakarta elite organised a rebellion that was defeated by Daendels. Daendels demanded that the sultan took responsibility for the rebellion and accepted the new order. Hamengkubuwana II however refused.

Hereafter 3200 VOC troops forced the sultan to give his throne to his son Hamengkubuwana III. Daendels concluded new treaties with Surakarta and Yogyakarta in 1810. The rent that the Dutch paid for the coastal regions was stopped as from now on the Netherlands demanded sovereignty over Java. Hereby the Javanese court lost an important means of income and the main reason to accept Europeans in their kingdom (1).

I.3.2 VOC SURRENDERS TO BRITISH

In total 60 British ships conquered Batavia in 1811 and a new Governor-General was installed. Hamengkubuwana II retook his throne in 1811.

King Pakubuwana IV now entered the scene. Pakubuwana IV promised in secret letters to sultan Hamengkubuwana II to support him if he would fight against the Europeans. In reality Pakubuwana IV only hoped that this would lead to an offence against the Europeans, that would trigger an European destruction of the Yogyakarta kingdom. The British discovered the correspondence and began secret negotiations with crown prince Hamengkubuwana III to destruct Yogyakarta. Ultimately the sultanate was conquered and Pakubuwana IV did not come to the rescue of the sultan.

Sultan Hamengkubuwana III and king Pakubuwana IV
Hamengkubuwana III was put on the throne again in 1812 and his father exiled. The conquest of Yogyakarta meant a big humiliation for the aristocracy. For the first time in history it was clear that Europeans had hegemony in Java.

The attempt of Pakubuwana IV to get rid of the Yogyakarta kingdom had failed. The Europeans now not only annexed more land, toll-gates and markets from Yogyakarta, but also from Surakarta. The British gave the Chinese the administration of the toll-gates. The Chinese administration led to more corruption and abuse of Javanese citizens.

Pakubuwana IV created a new conspiracy. This time he contacted discontented Indians to destruct the European government and the Yogyakarta kingdom together. The plot was discovered and those involved were shot or exiled, yet Pakubuwana IV himself was spared.

Many problems arose in Java. The Europeans started to interfere more in court life and in its intrigues. At both courts corruption enhanced. Europeans and Chinese started to ask more taxes and rent for plantations and land from aristocrats and farmers. The farmers had to pay in cash and hereby became dependent upon Chinese moneylenders, who abused their power. The role given by the Dutch to the Chinese gained in significance. This worsened the tensions between Javanese and Chinese citizens. As the installation of more toll-gates continued, rural trade was discouraged.

After the Napoleonic wars, Java was returned to the Dutch. However, the British episode had brought many changes. Deliberately Javanese institutions had been used, reformed or abolished. Europeans now assumed and claimed colonial rule (1).

I.3.3 JAVA WAR

Dipanagara was the eldest son of sultan Hamengkubuwana III. He grew up during the reign of his grandfather. A reign what was dominated by intrigues. Dipanagara was raised by his grandmother in an isolated residence. He studied Javanese history and Islam. Dipanagara particularly disliked the court for its intrigues and immoral corruption. Dipanagara was a devote Muslim and went on a pilgrimmage to holy sites connected with the Mataram dynasty. *He had a vision in which the Goddess of the Southern Ocean promised to help him. According to Dipanagara this was a sign that he would be the future king of Java.* Dipanagara was to become one of the most well-known persons of Javanese history.

The problems in Java increased. The rice harvest was poor and an epidemic of cholera spread. Mount Merapi erupted. As the Dutch government claimed ownership of all the land, the Governer-General forbade aristocrats to lease land any longer. Rebellion broke out, led by Dipanagara. Dipanagara fought against the court and against the Europeans. The Dutch sent troops to capture Dipanagara. The Java War (1825-1830) broke out. Dipanagara had the support from many discontent aristocrats, 15 out of 29 princes and the Islamic leaders. The Europeans were assisted by the kingdoms of Surakarta and Yogyakarta. Dipanagara initially controlled part of Java, but eventually was defeated by the Dutch and their allies. Dipanagara died during exile.

After the Java War, the Dutch annexed more land in the outer regions from both courts. Because of this annexation, the courts lost their power and mainly retained a symbolic value. Most aristocrats from now on supported the Dutch and the latter revised their policy toward the elite. The Dutch rejected the anti-feudal attitude from Daendels and the Napoleonic period and treated the elite as allies (1).

I.3.4 TRUE COLONIALISM

In 1830 true colonialism started. The Dutch possessed whole Java now and were determined to exploit and benefit from it.

Since 200 years the VOC was involved with Javanese trade, but had never been able to gain wealth from it. Only a few corrupt VOC officials had become very rich from their malpractices. Solely coffee plantations were profitable, yet this profit was also lost to the large military and administrative expenses. This had to change.

The Dutch designed a new cultivation system (cultuurstelsel). Theoretically this meant that Javanese villages had to pay land tax to the Dutch government. Every village should designate part of their land to the cultivation of tropical produce required by the Dutch for their export. The products were sold for fixed prices to the Dutch. With this money villagers could pay their land tax. When the production could not cover the land tax, the villagers had to look for other ways to fulfil their obligations. In practice this led to cruel exploitation of villagers as local officials raised the land tax whenever they wanted. Abuse and corruption by these local Dutch and Javanese officials increased, as they were not checked upon by the central government.

The Javanese officials who controlled the implementation of the cultivation system consisted mainly of aristocrats. This Javanese elite also abused its position to gain personal wealth, and in fact was often encouraged to do so by the Dutch. They demanded compulsory labour and personal services from their subordinates. This led to a further alienation between aristocrats and their Javanese compatriots.

For the Dutch government the cultivation system brought large profits thanks to the strong growth of the Javanese population which led to a surplus of labour. The Netherlands regained its prominent position in the world trade of tropical products. The exploitation of Javanese villages enriched the Dutch nation: in the Netherlands state debts could now be paid, taxes decreased and railways, waterways and fortifications built.

In the 1840s problems arose. Due to too frequent rotations of crops the soil got depleted with bad harvests as a result. Famines broke out, not because there was no rice available, but because poor Javanese villagers could not afford to buy rice. The aristocrats and Chinese traders refused to lower the price of their stored rice. Epidemics spread. The Dutch government increased the land tax and many villagers left the rural areas, which led to a further drop in production. The export of tropical produce decreased and a financial crisis arose in the VOC.

In the Netherlands opposition arose against the cultivation system and the exploitation of the Indonesians. In 1860 a former Dutch official wrote a book, titled “Max Havelaar”, about the corrupt and oppressive Dutch colonial regime in Java. It brought about a political debate in the Netherlands that led to the abolishment of the cultivation system. Villagers were no longer forced to grow crops for Dutch export. No longer all land was owned by the Dutch government either. In 1870 Javanese were able to buy land from the state and foreigners could lease it. However these reforms only worsened the position of ordinary Javanese citizens, as the land tax still had to be paid. This again gave aristocrats and Chinese tools to exploit the poor.

The Dutch officially had hegemony, but they used royal authority to maintain peace. The VOC let the royal elite rule their kingdoms under Dutch supervision. As the royals had little political influence, they got more involved in cultural and artistic events, like prose, literature, music and wayang.

During the time of the cultivation system, Javanese aristocrats had abused their position and demanded compulsory labour and personal services from their subordinates. The common Javanese disliked them for it and the new Dutch liberal ideas criticised it. The Dutch now tried to reform the administration and thereby limit these abuses. Increasingly the elite were bypassed and compulsory labour eventually prohibited (1,2).

I.4 FIRST CONCEPT OF INDONESIA (1900-1942)

I.4.1 ETHICAL POLICY

In 1910 almost whole Indonesia was under Dutch rule. Indonesia could be colonised by a relatively small Dutch military because there was no idea yet of one nation. The

country had been divided in many kingdoms and isles, which fought each other, instead of resisting the Dutch together.

Now that there was no territory left to be conquered and protests in the Netherlands arose against the oppressive colonial rule, the Dutch theoretically changed their policy. Their main purpose was no longer the exploitation of Indonesia, but the welfare of its citizens. It was called the "Ethical policy" and it focussed on education, irrigation and emigration. In practice welfare was less important than gaining profits from Indonesian export products. The outer islands became the new area for economic development and export. Emigration of people from densely populated Java to underpopulated outer islands was stimulated. These emigrants worked on plantations to secure export revenues for the Dutch. In Java the corruption, mismanagement and maladministration was enormous. The overpopulation led to a rise in unemployment and poverty. Violent and criminal activities became more prevalent. The emphasis on education led to the opening of schools. The fees however could only be afforded by the rich. Again the Dutch Ethical policy decided what was best for Indonesians and then let them pay for it. Subsequently only the rich could benefit from it. The welfare reforms in general brought no welfare. Decentralisation and more Indonesian involvement in government was another aim of the Ethical policy. Therefore a people's council (Volksraad) was installed. However, the Volksraad never turned into a real parliament because the Dutch did not want it to. Indonesia remained a colonial state that was governed by a small European country (1).

I.4.2 PROLIFERATION OF ORGANISATIONS

At the beginning of the twentieth century Indonesians started to organise themselves based on different religious, ideological, political, ethnic and socio-economic backgrounds. Many organisations were established.

Different groups started to divide themselves in separate organisations:

The **Javanese elite** could be divided into the old and new elite. The old elite consisted of aristocrats who got their wealth and status by birth. The new elite achieved their position through their own achievements, regularly based on good education. In general the old hereditary elite looked down on the newcomers.

Muslims could also be divided in different groups, which varied from very strict to liberal Islam adherence. At that time being a muslim meant to most Javanese little more than just a nominal commitment. Fulfilling the Islamic obligations, like praying 5 times per day and fasting, were neither essential nor common. Their religion and culture were more Hindu-Buddhist and mystical in nature. *An example of an Islamic organisation was the establishment of "Muhammadiyah" in Yogyakarta. It was a reaction against Christian missionaries. Its aim was to purify Islam in Indonesia from pre-Islamic customs and superstitions. Muhammadiyah embodied missionary, educational and welfare organisations. It spread throughout the country. Schools, clinics, orphanages, poorhouses, libraries, mosques and prayer houses were built in its name.*

Labourers organised themselves in trade unions. Initially the trade unions were successful and able to improve the incomes and work conditions for their members. As the number of members increased, the Dutch started to repress the trade unions. When the economy collapsed and unemployment rose, the position of the trade unions weakened even more.

Socialists established different political parties. *The first Communist party in Asia was erected, called "PKI" (Indonesian Communist Party*). *Communism within PKI had a strong Indonesian character. The classless society was pictured as a reincarnation of the Majahapit empire before the arrival of Islam and the Dutch. Not as much Marx or Lenin, but Dipanagara from the Java War was seen as a hero.*

The different organisations started to compete with each other and conflicts arose between them. Initially the Dutch saw these organisations as a positive development and part of the new Ethical policy. When the organisations however grew stronger, the Dutch perceived them as a threat to colonial rule. Repression was intensified. The Dutch arrested, imprisoned and exiled leaders of political parties and prohibited their existence.

After the arrest of the PKI leaders, the remaining PKI members started a rebellion against the colonizers. The Dutch crushed the rebellion *(13,000 members got arrested, some were shot, 4,500 were imprisoned and more than 1,300 sent to a specially built prison camp).* This defeat of the PKI rebellion had a big impact on the moral of the Javanese. Not until the Second World War did Javanese dare to stand up against their colonizers on a large scale.

As a child and young adult Sukarno had attended the European school system. He had read many books and was influenced by Hindu, Buddhist, Islamic and Western ideas. Sukarno was convinced that the anti-colonial movement had to be united. He believed that the different Islamic, socialist and other ethnic groups should be subordinated to Indonesian nationalism. Sukarno founded a new political party PNI (Partai Nasional Indonesia) after the destruction of PKI. The aim of this party was independence for Indonesia.

The Dutch in Indonesia switched from the ideas of the Ethical Policy to conservative right ideas. Now the difference between Indonesians and Europeans was emphasized and the Dutch claimed that Indonesians were better off if they were treated in a paternalistic way by the Dutch. The colonizers became worried and insulted by Sukarno who criticized colonialism during public gatherings. Meanwhile Sukarno's nationalistic ideas became widespread. Sukarno was arrested, convicted of being a threat to public order and put in jail. Hereafter PNI suspended its activities.

Until now there had been no common language that all Indonesians spoke. Different isles and regions had different languages. Literature however started to appear in one common language: Malay. The Malay language was generally accepted as it was a neutral one. For instance, the outer islands would never accept dominant Java to deliver the new Indonesian language. Intellectuals started to rename the Malay language as the national Indonesian language (Bahasa Indonesia). This common Indonesian language united the Indonesians (1).

I.4.3 ECONOMIC CRISIS

As Indonesia's exports mainly went to Western countries, the European and American economic crisis of the 1930s also hit Indonesia. Dropped exports resulted in a severe economic crisis in Indonesia. Incomes decreased and unemployment increased. Japan started to penetrate the Indonesian market with cheap Japanese products and employed Indonesians. In response the Dutch introduced licences and quotas solely for Japanese import. Hereby the Japanese were pushed out of the Indonesian market. Indonesians saw that the inexpensive Japanese goods were replaced by costly Dutch ones. The Indonesian employees got fired and as usual the Dutch offered Chinese citizens jobs.

The Dutch political climate became even more right wing in the 1930s. The Governor-General opposed Indonesian nationalism, regularly prohibited political gatherings and minimized the influence of the Volksraad. Schools were searched or closed and many teachers dismissed from teaching. PNI was dissolved in 1931 as its leaders felt that after Sukarno's imprisonment the party was prohibited. Political leaders were arrested and exiled. Sukarno was freed, yet in 1933 arrested again and exiled. Now many Indonesian nationalists realized that in order to gain independence they should use moderate methods and cooperate with the Dutch, as non-cooperation would lead to prison or exile. However, over and over again the Dutch proved that they were unwilling to give the Indonesians any kind of autonomy. Finally all hopes for progress in cooperation were lost (1).

I.5 DESTRUCTION OF COLONIALISM (1942-1950)

I.5.1 SECOND WORLD WAR

In Europe and Japan fascism grew stronger. Leftist Indonesian political leaders wanted to oppose fascism together with the Dutch. The Indonesians hoped that the fascist threat in Europe would inspire the Dutch to give the Indonesians some kind of autonomy. The Dutch however remained strongly opposed to any Indonesian autonomy and wanted no political changes in Indonesia now, as they were too concerned and occupied with internal policy in the Netherlands. The Dutch demanded stability in Indonesia and became more restrictive toward the political organisations.

The Second World War started in September 1939 when Hitler invaded Poland. In February 1940 the Dutch government declared that there would be no Indonesian autonomy or parliament. On the 10th of May 1940 Hitler conquered the Netherlands and the Dutch government went into exile in England. The same day martial law was implemented in Indonesia and public political activities prohibited. In September 1940 the alliance between Germany, Japan and Italy was concluded. The Japanese leaders spoke in public about their willingness to liberate the Indonesians from the Dutch occupiers. In response the Dutch expanded their military troops in Indonesia (1).

I.5.2 JAPANESE OCCUPATION

The Japanese invaded Indonesia on the 10th of January 1942. Most Indonesians gave no support to Dutch military forces and some attacked Dutch troops and civilians. In

Java the Dutch surrendered on March 8th 1942. The occupation by the Japanese lasted 3,5 years. It was one of the most significant periods in the history of Indonesia**.** The Japanese rule altered the Indonesians in such a way that the Indonesian Revolution became possible. Particularly the Javanese were indoctrinated and received militairy training and arms. The older Indonesian political leaders were put in a postion where they could connect with larger populations. During Dutch colonization there was not much political awareness among Indonesians in rural areas. This changed during the most repressive, destructive and cruel colonial order the Indonesians had ever faced.

The Japanese divided Indonesia in 3 regions. Economically Java was least important and contained mainly human resources. The Japanese acknowledged the Javanese political sophistication and encouraged nationalism in Java. Sumatra possessed strategic resources and only when the Japanese realized they were losing the war, nationalism was stimulated on this island. Kalimantan and East Indonesia were economically crucial to Japan. The Japanese regarded this area as politically underdeveloped and Japanese regime was most repressive here.

The Japanese interned most Europeans in camps. Only Europeans crucial to the industry were not held in captivity but forced to work. Conditions in the camps were poor *(approximately 170.000 people were imprisoned: 40% of male civilians, 20% of Dutch soldiers, 13% of female civilians and 10% of children died in the camps).*

In order to establish and maintain their conquest the Japanese immediately put a halt to the revolutions, looting, violence and personal attacks on Europeans, Chinese and Javanese Christians by Indonesians. If required political leaders were arrested, shot or beheaded.

Like the Dutch, the Japanese wanted to reign Indonesia for their own financial benefits. Most important to Japanese was therefore reorganisation of the Indonesian trade and economy to support Japan and its army. Extreme hardships followed: inflation, shortages, famines, profiteering, forced labour, corruption and black markets prevailed.

Besides from being economically chaotic, the Japanese occupation was characterized by terror of military police, beatings, rapes, arrogance, cruelty and the demand to salute every encountered Japanese individual. Those Indonesians who initially perceived the Japanese as their fellow Asians and liberators, soon found out that one colonial regime was just replaced by another.

Japan tried to ban Western influences. The Dutch and English languages were prohibited. Without Western literature and books, higher education became virtually impossible during the Japanese occupation. Batavia was renamed Jakarta again and Dutch statues were removed.

The Japanese started an intensive propaganda. They declared that both Indonesians and Japanese should build a new Asian order together. Radio, movies, drama and wayang were used for propaganda purposes. The Japanese message was mainly delivered in the common Indonesian language and thereby enforced its use as the national language.

The Japanese prohibited all political organisations and erected new ones under firm Japanese control. Indoctrination and strict discipline characterized them. Some organisations had a semi-military character. The Japanese realized that if they wanted to influence large populations, they should use some Indonesian leaders as key figures in these organisations. Sukarno joined and in his turn he used the Japanese propaganda campaign to spread his own nationalistic messages.

In an attempt to gain support for their war, the Japanese promised Indonesians more autonomy and political influence.

The Japanese needed more labourers to secure their Indonesian resources. Therefore mainly Javanese farmers were forced to work as "voluntary labourers" for the Japanese. *(Some 200,000 to 500,000 men were torn apart from their families. These families subsequently faced even more poverty. Only approximately 70,000 of these "voluntary labourers" survived the war).* The Japanese government also obligated Indonesians to sell rice at low prices to the Japanese army. Indonesian officials who controlled this forced rice sale were deeply hated by Indonesian farmers.

When it became apparent that the Japanese were losing the war, the number of protests and revolts by Indonesians increased. Underground organisations were established and planned the gain of national independence. Once defeat was inevitable, the Japanese stimulated Indonesian revolutionaries in order to frustrate a Dutch reconquest. Therefore a committee was installed by the Japanese that had to prepare the Indonesian independence. Sukarno was a member of this committee. Sukarno promoted nationalism and was convinced that religion and politics should be kept apart. The Islamic leaders did not agree with him and desired to give Islam a more prominent role. However, all involved realized that they should unite to achieve independence. Sukarno explained that his state ideology "Pancasila" is founded on 5 basic principles: belief in God, nationalism, humanism, social justice and democracy.

In May 1945 Germany surrendered. After liberation of the nazis, the Allies could focuss on the war in Asia again. On August 6th and 8th 1945 atomic bombs on Hiroshima and Nagasaki were dropped. Indonesia was now promised independence by the Japanese. On August 15th the Japanese surrendered. On the 17th of August 1945 Sukarno declared independence of the Republic of Indonesia (1).

I.5.3 THE REVOLUTION

The Indonesian struggle for independence was marked by fragmentation, disorder and chaos. All the different political, religious and social groups had only one thing in common: their desire for independence. These groups did not act as a coherent group. The strong diversities and their poor communication with each other almost made the Dutch win the battle. However thanks to the Indonesian resistance and support of the United States and United Nations the Indonesians were finally liberated from colonial rule.

In August 1945 a Republican government was installed in Jakarta and Sukarno became President of the Republic of Indonesia. The preparatory committee had designed a constitution in advance and now implemented it. Unfortunately the Japanese had dismantled the army and as a result the new Republic could not count on

a well oganized and equiped military force. Now local initiatives were taken to form armed forces and there was no central authority they could obey.

Javanese courts supported the Republic, but many kings from outer islands did not. In the past the latter had worked together with the Dutch and grown rich from it. Many feared that Republicans were anti-aristocratic. A Republic might restrict the privileges and incomes of the aristocratic elite.

Soon the idea of independence and freedom received support of most Indonesians. Especially the younger generation was thrilled by the excitement of a revolution. The Japanese started to withdraw from Indonesia. Sukarno prevented that violence broke out against Japanese. Sukarno had an extraordinary talent to speak in public and thereby influence and motivate Indonesian masses. This time he convinced the Indonesians to calm down and so they did.

The Dutch wanted to rule Indonesia again and punish the ones who had collaborated with the Japanese, but could not do this themselves in 1945. They hoped the British would help them and take care of the reconquest of “their” colony. The British however had another mission: they wanted to free the Europeans in the camps and accept the surrender of the Japanese. The British accepted the Japanese surrender in Java and Sumatra, and the Australians took it in East Indonesia.

Tensions accumulated in Java and Sumatra as more Allied troops entered Indonesia. Republican resistance resulted in various violent clashes throughout the country in which thousands of people were killed. The British used air and naval bombardments. Ceasefires were repeatedly violated. In Surabaya the heaviest battle was fought and it still constitutes the national symbol of the Revolution. The fierce Republican resistance, especially in Surabaya, shocked and showed the world that the desire for freedom had a large popular support in Indonesia.

As the Allied troops had first arrived in Jakarta and secured order there, the situation in the capital city did not get out of hand. Also the central Indonesian leaders in Jakarta wanted to gain independence through diplomacy instead of fighting. They had neither influence nor sympathy for the violent Revolution in the countryside. The Dutch government was not willing to negotiate with Sukarno as they saw in him a collaborator with the Japanese. The Dutch wanted to deal with Sjahrir. Sjahrir desired independence through a democratic socialist revolution. He was known to be anti-aristocratic and anti-fascist. His relationship with the Republican army, in which many had served for the fascist Japanese, was poor and marked by distrust. Sjahrir was made Prime Minister and talks with the Dutch began.

In the countryside different social, religious and ethnic groups started competition and fights with each other. Also intimidation, kidnapping and killing of Indonesians who had collaborated with the Japanese occurred.

The popular sultan Hamengkubuwana VIII of Yogyakarta made some radical changes in his kingdom after the declaration of independence by Sukarno. He reduced the power and incomes of the court administration and increased the number of village councils and headmen. He abandoned the head tax and implemented the national Indonesian language as the official language instead of the original Javanese. The

sultan established his own army and thereby became also an army officer himself. During the Revolution Yogyakarta became the capital city of the independent Republic of Indonesia. The Dutch had occupied the only two cities that owned a university, being Jakarta and Surabaya. The sultan opened his palace to house the newly erected Gadjah Mada University of Yogyakarta. A court insider mentioned that: *"the Revolution cannot smash the palace doors, because they are already wide open"*.

During the Revolution political parties were installed, of which the most significant were: Communist Party (PKI), Socialist Party, Islamic Party "Masyumi" and Indonesian Nationalist Party (PNI).

The political influence of the Republican army gained in significance. The military could be divided in two groups: professionals with a former Dutch training and guerillas who entered the army during the Revolution.

The Indonesian case was for the first time addressed in the United Nations (UN) in January 1946. This UN involvement turned out to be significant.

The Australian troops handed East Indonesia over to the Dutch. The British turned the rest of the country over to the Dutch, except for Java and Sumatra. The British demanded that the Dutch and Republicans would first come to a peace agreement, before they handed Java and Sumatra to the Dutch. The Dutch wanted to create a federal United States of Indonesia, in which the Republic would be one of the federal states and the Dutch queen would be the head. Sjahrir insisted that the Dutch had to recognize the Republican authority in Java, Sumatra and Madura first. Both parties made these concessions and the first peace agreement was concluded in November 1946. However, both sides received much criticism from the homefront for their concessions. Many Indonesians wanted to get rid of the Dutch completely and were dissatisfied with Sjahrir's policy. The arranged ceasefire did not last long.

After the war in the Netherlands, the Dutch did not have enough finances to pay the 100,000 soldiers in Java. They therefore needed access to products of Java and Sumatra. In order to achieve this access, the Dutch attacked the Republic on 20 July 1947. The Dutch conquered most of the Republic. Only strong American and British disapproval stopped the Dutch from conquering Yogyakarta too, in order to install a Republican government more to their like. Now the UN entered the scene. Especially America, but also Australia, India and Russia strongly objected the Dutch policy, as the Indonesians apparently desired freedom. The UN started to examine the Dutch actions more closely. The UN demanded a new ceasefire and agreement, which was ordered by the Dutch and Sukarno. Subsequently the Republican government fell and a new emergency cabinet was installed with Sukarno as President.

The Dutch set up an increasing number of federal states in their conquered territories. They refused to render the Indonesians some kind of authority and hereby lost the last goodwill they had. Within these federal states most Indonesians were supportive of the Republic and disliked federalism.

In 1948 chaos dominated the Republic in Java. The size of its territory was reduced by the Dutch conquests. The remaining area was densely populated and now also faced

about 6 million refugees and Republican soldiers. There was a shortage of rice. The Republican army disintegrated into several groups that started to fight each other. Chinese and aristocrats were being murdered. Attacks from West-Java on the Republic by a militant Islamic guerilla started. This guerilla was led by a Javanese mystic who fought both the Dutch and the Republic. The rebellion coincided with great terror and banditry and lasted until its leader was executed in 1962.

In 1948 Musso, a former PKI leader, returned from Russia and restored his position in the Communist Party as leader. Musso encouraged the working class to demonstrate, strike and take over land from the elite. Musso's communist ideas threatened the Republican policy, aimed at winning support from the United States of America. Fights broke out between those who supported the PKI and those who supported the Republicans. PKI supporters took over the Madiun area and attempted a coup in September 1948. Sukarno made an appeal over the radio to support him instead of Musso. It was effective. Republican forces conquered Madiun. Musso was killed and thousands lost their lives. Madiun became very important in the Revolution, as the defeat of the communist rebellion by the Republicans won America's sympathy. The USA could use anti-communist Indonesia as an ally in the upcoming "Cold War" between America and the Soviet Union.

When the Dutch decided to attack the rest of Java in December 1948, the conquest of Yogyakarta and the Republican government was easy. Sukarno was captured. The Republicans hoped their defeat would become a diplomatic success and it did. World-opinion turned against the Dutch and the UN Security Council was angered. The Republican army however felt betrayed by the quick surrender of the Republican government, while they were sacrificing their lives for independence. They did not understand the strategy of the politicians. The armed forces began a guerilla war that reduced the areas that were occupied by the Dutch.

The Dutch showed a striking disability to comprehend the alterations that had taken place in the Indonesian society. They truly believed they still had a right to reign this Asian country. The Dutch even asked sultan Hamengkubuwana IX to become the leader of a new Javanese state under Dutch control. The sultan refused and resigned as leader of the Yogyakarta area in January 1949. Also the cabinets of East Indonesia and Pasundan resigned out of protest against the Dutch. These resignments embarrassed the Dutch in front of the international community.

Despite new ceasefires, mediated by the UN, the guerilla war went on.

The USA condemned the Dutch actions in public and warned the Dutch that they would stop the reconstruction aid the Dutch received after the Second World War. The Netherlands depended heavily on this American aid program and could not afford to lose it. In January 1949 the Security Council of the UN demanded the installation of an interim government and the transfer of hegemony. And so it happened. Initially the Republican army was unwilling to recognize the authority of Indonesian politicians, who they believed had betrayed the Republic. However, when Sukarno threatened to resign, the army gave in.

Sultan Hamengkubuwana IX organised the transfer of military troops under Dutch authority to Republican military authorities.

Finally the combination of strong UN and USA disapproval together with the Republican military resistance forced the Netherlands to hand sovereignty to Indonesia on 27 December 1949 (1).

I.6 SUKARNO (1950-1967)

I.6.1 MULTIPARTY DEMOCRACY

Now that independence at last was achieved, the Indonesian political leaders wanted to establish a representative democracy. This proved very difficult to install for several reasons. Indonesia is a large and very diverse country. Indonesians had only known the Dutch and Japanese police states and thus missed a proper role model. As most Indonesians were illiterate, poor and used to paternalistic and authoritarian guidance, they were not able to demand responsible behaviour from their politicians.

After the Japanese occupation and Revolution, Indonesia encountered many socio-economic difficulties. Plantations and industries were destroyed. The growth of the population still increased and food-shortages resulted. Farmers lost part of their land and thereby could not earn a living of it anymore. They were forced to do wage labour and move to the cities. Unemployment increased and the government offered many people jobs in the bureaucracy. Low salaries, inefficiency, maladministration and corruption marked this expanding bureaucracy. The economic recovery was slow. Export stayed behind. Infrastructure was poor and had a negative influence on the export. Inflation remained high.

As Java possessed the capital city and government, most outer islands felt neglected.

Sukarno's government acknowledged the importance of education and the number of schools and institutions increased. Literacy subsequently increased too. In schools, literature and mass media the common Indonesian language was used, which enforced its position as the official national language.

The decentralised army needed to be reorganized and its role, structure and leadership determined. Civilian politicians wanted control over the army, yet military professionals had authority. The army did not trust civilian politicians due to their "betrayal and weakness" during the Revolution. Continuous competition between politicians and army emerged.

Proliferation of political parties occurred, yet only a few played a significant role. The Islamic Party "Masyumi" was the largest. They kept religion apart from politics. So Masyumi did not strive for an Islamic state, but for national unity. The Indonesian Nationalist Party (PNI) was the second largest. The Indonesian Communist Party (PKI) soon became one of the largest parties and its supporters were mainly workers. At last we also need to mention the Socialist Party (PSI) and Nahdlatul Ulama (NU). The latter represented the interests of Orthodox Muslims.

Indonesia entered the United Nations (UN) in 1950.

In 1950 the political leaders in Jakarta developed a parliamentary system similar to the Dutch multiparty democracy, in which a cabinet was responsible to a parliament. The first cabinet consisted of Masyumi with PSI and was replaced by a Masyumi-PNI coalition after 7 months already.

This Masyumi-PNI government accused PKI of organizing strikes and attacks on a police station. Thousands of PKI members got arrested. Communist leaders decided to emphasize nationalism instead of working class demands. Subsequently PKI grew in a spectacular way and both Masyumi and PNI felt threatened by them.

The Masyumi-PNI coalition resigned and was replaced by a new one. This cabinet aimed to decrease the size of army and bureaucracy. A conflict with the army arose. *Out of* protest to the planned reforms in the army, a large demonstration with tanks, artillery and civilians was organized by the central army command. Sukarno spoke to the gathered crowd and on the radio. He requested calm. Sultan Hamengkubuwana IX thereafter resigned as Minister of Defence and central military commanders lost power. The army became even more decentralised and civilian politicians interfered more in the military. The army received less money from the government and started to seek for new ways to finance their existence. The army's involvement in smuggling enhanced.

When the police killed 5 peasants during removal of squatters on a terrain destined for foreign companies, the PKI and PNI demanded the fall of the cabinet. A new cabinet with PNI and some minor parties was installed. Politicians became more and more interested in holding power, than performing politics. Corruption and scandals increased.

Relations between Communist China and Indonesia became more friendly.

The growth of PKI was tremendous. PKI was the richest political party and probably the Chinese Embassy forced Chinese entrepreneurs to donate money to the PKI. But money also came from fees paid by members and funds. Many poor peasants joined PKI as they stood up for their rights, others joined because of its good work in the community. For instance schools, houses, bridges, roads and dams were repaired by PKI. PKI also organized and paid for literacy courses.

After 5 years the promised parliamentary elections finally took place in 1955. More than 91,5% of voters actually casted their votes. The four big parties were PNI, Masyumi, NU and PKI. The amount of votes for PKI shocked and threatened the Jakarta politicians. There was a big difference between voters in Java and those in the outer islands. In the outer islands Masyumi won and in Java there was a balance between PNI, NU and PKI. The present cabinet however tried to postpone the installation of the elected parliament and new government as much as they could. A PNI-Masyumi-NU coalition was formed in order to keep PKI out. In March 1957 the first freely chosen parliament in Indonesia was established.

Sukarno mentioned during his opening speech to the chosen parliament that an Indonesian style democracy should be based upon concensus. *This in contrast to Western style democracy in which the majority decides. Sukarno disliked the Western exchange of arguments in dialogues between government and opposition in the*

parliament. Sukarno later referred to his Indonesian style democracy as “guided democracy”. Sukarno wanted to get rid of the different political parties and replace them with functional groups (for instance: youth, workers, religions and regions).

The relation with the Dutch deteriorated, mainly due to Dutch refusal to render their authority over Irian to the Indonesian government.

PKI strongly opposed the Dutch refusal to surrender Irian. More and more the ideas of PKI matched the ideas of Sukarno.

Increasingly the Jakarta politicians illegally gained wealth through corrupt practices. They hereby set an example and their subordinates copied their behavior. It was striking that corruptors did not receive punishment in court and could continue their malpractices. Social injustice prevailed. *Let us give an example. The well respected and brave journalist and novelist Mochtar Lubis, known for his high moral standards, alleged corruption of the Foreign Minister. Mochtar Lubis himself was now arrested and sentenced to 9 years of imprisonment or house arrest. The Foreign Minister got away with paying a small fine.*

The Indonesians started to blame and attack the Chinese community for the encountered economic difficulties. Especially in outer islands and more strict Islamic regions in Java the Chinese citizens had a hard time.

In the outer islands Sumatra, Kalimantan, Sulawesi and Maluku army officers took over the civil government. They demanded more autonomy from Jakarta. These military forces had local civilian support.

Sukarno was more content with PKI than PNI now, as he detested the corruption scandals within the government and PNI. PKI had never been in the position to abuse power and its image was therefore still clean. Also the revolutionary spirit of PKI attracted Sukarno.

The country was falling apart and Sukarno installed martial law in March 1957, which placed the armed forces in charge of the whole nation.

So in 1957 the multiparty democracy had failed, corruption and social injustice became the norm and economic problems remained (1,3).

I.6.2 GUIDED DEMOCRACY

Both Sukarno and the military leaders introduced guided democracy. Sukarno dominated it. Sukarno was an excellent manipulator and some believed he was a dictator as well. Sukarno increased his power by manipulating and threatening other men in powerful positions. His policy was marked by intrigues and conspiracies. Sukarno had neither knowledge of economics nor authority within the army. Sukarno preferred revolutions over stability. As his first multiparty democratic experiment had failed, Sukarno and his ruling elite now became more repressive. Their suppression resembled the Dutch and Japanese rule, which at least had been more effective than the system of democracy with multiple political parties. Sukarno continued to publicly

announce that he preferred a one-party-system, like the Soviets had, over a multiparty democracy.

The political parties themselves were too busy with both internal conflicts as well as competing with other political parties, that they could not strongly defend the multiparty democracy system together.

In May 1957 a National Council was established that presented 41 functional groups. The members of these functional groups were the former civilian politicians from the different political parties.

The army wanted to enhance its role in the newly formed guided democracy. Formal cooperations between civilians and army were established. Under martial law the position and power of the army indeed grew stronger. The military started to make more and more arrests. Many civilians and especially PKI members got arrested. In contrast to Sukarno, the army disliked PKI. Commanders restricted political activities and some politicians got arrested for corruption.

Protests against Sukarno and his policy became stronger. *We will give a few examples. The military dissidents from the outer islands wanted to cooperate and organise an election for a new President, replace the central military leaders and abolish PKI. Another example: Masyumi rejected Sukarno's guided democracy and claimed that communism and PKI were forbidden for Muslims. Several attempts to assassinate Sukarno evolved.*

In 1957 UN resolution to put an end to Dutch reign in Irian failed. Now Sukarno promoted anti-Dutch sentiments. Dutch companies, for instance the oil industry, were taken over by the Indonesian army. The central military command became in charge of economic power and thereby also increased its political power toward regional commanders and the civilian government. Mismanagement, inefficiency and corruption inside these companies increased.

When Sukarno was out of the country, the military dissidents from the outer islands gathered and established a rebel government, known as PRRI. PRRI received support from countries that were dissatisfied with Sukarno's policy and PKI. Among these countries were America, Malaya, Singapore, the Phillipines, Taiwan and South Korea. The USA secretly supplied the rebels with weapons. Sukarno returned and insisted that the rebellion should be eliminated. The resulting warfare lasted for 3 years and several thousands died. Finally the PRRI rebellion was defeated.

The rebellious military officers from the outer islands were expelled from the army and now the remaining army contained mainly Javanese. Hereby the contrast between privileged Java and the disadvantaged outer islands grew stronger.

The general repression and firm conquest of PRRI made the military unpopular with civilians and Sukarno. Competition and tensions between the President, supported by PKI, and the army arose.

The relation between Indonesia and America worsened after the latter's support of the PRRI rebels.

On Independence Day in 1959 Sukarno restored the constitution of 1945 and explained the state ideology of guided democracy. It consisted of 5 Pancasila principles of the Revolution. Pancasila became the basis for all educational or governmental institutions and the media was obliged to support it.

With the abolishment of political parties, political leaders now influenced national policy through direct contact with Sukarno or the army.

Also the new guided democracy period was marked by economic disorder and difficulties. Inflation increased. The army enlarged its interference in economic affairs. The military excluded foreigners from trade in rural areas with the intention to harm the Chinese community. The army forced Chinese to move from rural areas to cities or China *(approximately 119,000 Chinese left Indonesia for China under pressure).* This policy only hurted the Indonesian commerce even more.

The army commanders started to arrest local Communists and continuously harrassed PKI activities.

The Netherlands tried to install independence for Irian with large support of its citizens. Out of protest Indonesia cancelled all diplomatic relations with the Dutch. Both government and army wanted to conquer Irian. They sought financial support from the Soviet Union. Russia wanted to increase its influence in Indonesia and thus gave economic and military aid.

The United States of America realized now that they should restore relations with Indonesia and win its goodwill again. Therefore they arranged that the Netherlands transferred Irian to Indonesia. America also offered economic assistance. The International Monetary Fund visited Jakarta for economic reforms.

England wanted to merge its territories in Borneo into a new Federation of Malaysia in 1963. Indonesia strongly opposed this, together with the Soviet Union and China. The latter two did not want another capitalist country in Asia. PKI members organised large and violent demonstrations against Malaysia. Sukarno increased the assigned army budget and put Soeharto in command. Sukarno proclaimed that the USA could "go to hell" with its aid. When Malaysia joined the United Nations in 1965, Indonesia withdrew from the UN Security Council and stopped all contacts with the Western world: IMF, Interpol and World Bank.

The power of PKI continued to increase. PKI had over 27 million members already and was worldwide the largest Communist Party in a non-Communist country. Political leaders that did not want to cooperate with PKI were suspended. Newspapers that opposed PKI were banned.

National instability rose. Inflation increased with about 500% per year. Rice harvests were poor and subsequently the price of rice increased with about 900% per year. PKI encouraged its members to seize land from their landlords throughout the country. Burnings, kidnappings and killings spread. Foreign businesses were taken and managed by the army. Protests within the military arose against the enormous corrupt

practices of some generals. The army splitted up in several fractions which either supported Sukarno or the central army command.

A coup was attempted in Jakarta in October 1965. Soeharto claimed control of the army and promised to protect President Sukarno. The army blamed PKI for the attempted coup. PKI however denied. The largest slaughter ever seen in Indonesia was initiated. The army arrested about 100,000 PKI members and leaders. They were interrogated, frequently tortured and imprisoned without trial. The army encouraged youths and students to find and attack PKI members. PKI buildings were burned. Throughout the whole nation at least half a million PKI members and leaders were murdered. NU encouraged the killings. Muhammadiyah declared a Holy War (jihad) against the Communists. To kill Communists became a religious duty. The slaughter ended in the beginning of 1966. PKI was destroyed. Sukarno condemned the killings. The army had encouraged and approved it. The military gained more and more power. Trials against the people who were said to have masterminded the coup were held and all leaders were executed.

In 1965 it was clear that also guided democracy had brought crisis to Indonesia (1,3,4).

I.6.3 COLLAPSE OF GUIDED DEMOCRACY

Soeharto was in control of the army now, yet Sukarno still had hegemony over civilian politics. The competition between Sukarno and Soeharto for power entered a new dimension. Soeharto's tactic was to stimulate violent chaos in Jakarta. Hereby he provoked that Sukarno gave him more power to restore peace and quiet again. Soeharto proposed Sukarno to fire a number of Ministers, but Sukarno refused. Soeharto told Sukarno that troops had surrounded the palace and Sukarno should escape. Subsequently Soeharto forced Sukarno to sign a document, called "Supersemar", in which Soeharto was given military and governmental authority to install order again.

Soeharto now ended guided democracy. PKI was abolished. Ministers were arrested and a new cabinet formed, led by Soeharto. The army was reorganised and many soldiers were arrested, suspended or retired. Officers who had been supportive of Sukarno's regime, were put on positions where their influence would be minimal.

Soeharto adopted pro-Western policies. He wanted to fulfil the Western requirements to receive economic assistance. In April 1966 Indonesia rejoined the UN and later the IMF. Sultan Hamengkubuwana IX played a significant role and was in charge of economic, financial and development affairs. The sultan introduced the economic reforms. The relationship with China was destroyed. Soeharto restored diplomatic relations with Malaysia. Japan offered Indonesia financial aid. The PRRI rebels were set free. The army returned American and British companies to their owners. The military budget was cut, but by now the army could rely on its own businesses and economic affairs.

Military officers who supported Sukarno wanted to kidnap Sukarno and persuade him to resist and fight Soeharto. Sukarno refused as he knew this would turn into a civil

war. Soeharto now started to please Sukarno's officers by offering them status or wealth, for instance jobs as ambassador was given away.

Finally Soeharto dismissed Sukarno as President in 1967. All his powers and titles were taken. Soeharto named himself Acting President. Sukarno's ideologies were abandoned, except for the Pancasila principles. Sukarno got house arrest. The first President of Indonesia died as a bitter and lonely man in 1970 (1,3).

I.7 SOEHARTO (1967-1998)

I.7.1 THE NEW ORDER

Soeharto was born in Java and only attended Muhammadiyah junior high school in Yogyakarta. He grew up with a religious teacher and healer (dukun) and was inspired by the Javanese mixture of mysticism and Islam. Soeharto highly respected and admired the sultan from Yogyakarta. Soeharto became General in the army and turned out to have qualities as a politician too.

Soeharto's policy is referred to as "the New Order", to set it apart from Sukarno's old political order. Initially many people embraced the changes Soeharto brought, in the hope to be relieved from all the difficulties of the past. Soon however they discovered that Soeharto's regime mainly benefitted a small newly created elite around the President. This elite consisted of family members, militaries and businessmen. Both in the army as well as in commerce Soeharto surrounded himself with this small group of allies, that he generously thanked for their support by illegal financial rewards.

In 1968 Soeharto was elected as President for a period of 5 years. Soeharto's reign was marked by paternalism and suppression. Soeharto wanted to destruct the old political parties. He controlled which political parties were allowed to continue their practices and which not. The PKI was destroyed. Political leaders Soeharto did not approve of were imprisoned without trial. Soeharto also removed those from police, navy, airforce and army who had supported Sukarno.

Soeharto's regime introduced pro-Western policies. Soeharto was able to stabilise the economy. Foreign companies were welcomed, yet indigenous businesses were not developed. Indonesian entrepreneurs soon realized that their interests were not served by Soeharto. Oil became most important for the state's economy. The government took control over the largest oil company in Indonesia. Inflation decreased. Once the economy reached stability in 1969, the government aimed at its development. Development Plans were designed that focussed on agriculture, infrastructure, export enhancement and diminishing import. The educational system remained of poor quality. Urbanisation continued and also Soeharto was unable to stimulate migration of citizens from overpopulated Java to outer islands**.** Unemployment increased.

In business Soeharto was particularly close with Chinese entrepreneurs, called "cukongs". These cukongs offered Soeharto's elite finances, international connections and business acumen. Soeharto preferred to deal with Chinese instead of indigenous entrepreneurs, because anti-Chinese feelings were strong in Indonesia. This meant they could never form a political threat to him. The elite protected the cukongs and

gave them opportunities, licences, inside information and shady business deals. In this way both the elite and the cukongs grew extremely rich.

Soeharto centralised the power within the military. All services came under his authority. The army also took over the regional governments. Provinces, towns and villages were run by military officials.

Soeharto had disregard for human rights. Political opponents were threatened, arrested, imprisoned and tortured on a large scale. Publications were banned. Amnesty International claimed that 55,000 to 100,000 political prisoners were held without trial in overcrowded jails.

Irian officially became an Indonesian province in 1969.

In 1970 all state employees were prohibited to join political parties and obliged to become a member of Golkar. Golkar was installed by the military as an organisation that coordinated cooperation between civilians and militaries.

Soeharto had respect for Islam as a personal issue, but he did not want it to interfere with politics. As political outsider, religion focussed on mission work. During Soeharto's harsh rule religiosity among Indonesians enhanced. Particularly the devotion to Islam grew stronger. However, also more conversions to other faiths occurred, like Christianity, Buddhism, Hinduism and Kebatinan. Kebatinan refers to the combination of mysticism with other religions. These conversions had both religious as well as political reasons. People tend to search for a moral identity in times of hardships and social injustice. Indonesians also had to commit themselves to a main religion for the outside world, as one might otherwise run the risk to be called an atheist and thus a Communist. The latter was dangerous. Also the stricter Islamic lifestyle obligations (for instance no alcohol, no pork, fasting, praying 5 times per day) might have made Indonesians switch to other faiths.

Indonesia had always been a multireligious nation, but in the past different religions were confined to different areas and ethnic groups. Now these different faiths occurred in one city, village or even family. It gave rise to violent conflicts between Muslims and Christians. Soeharto threatened to put fightings at halt by fierce military force. Hereafter the intensity of the conflicts declined.

Soeharto was extremely corrupt. His family, his elite and the cukongs grew extraordinary rich from their illegal practices. The news about their malpractices spread quickly and mainly students started to demonstrate against it. Violence against Chinese inhabitants broke out. The increased religiosity enforced the public's disapproval of immoral greed.

In 1970 corruption was investigated. The researchers concluded that corruption was present everywhere in the Indonesian society. Hereafter the so-called "anti-corruption" team was dissolved and nothing was done about it.

Elections for the parliament were held in 1971. This parliament consisted of appointed seats, that Soeharto directly controlled, and elected seats. Golkar won of course. The government now forced all political parties to merge in 2 parties. The Islamic parties

formed PPP (United Development Party) and the non-Islamic parties PDI (Indonesian Democracy Party). These political parties were not allowed to have their own organisations.

Soeharto was in 1973 again elected as President for 5 years. Now his Vice-President was sultan Hamengkubuwana IX. The sultan was admired by both Soeharto as well as the Indonesian population.

In 1974 Portugal wanted to create an independent state of their former colony East Timor. Indonesia strongly disapproved and invaded East Timor. The army misbehaved badly. Torture, rape and looting followed, particularly of the Chinese community. In 1976 East Timor became a province of Indonesia. The East Timorese had a different history and culture than Indonesians. They perceived Indonesia as an intruder that had occupied their country. Amnesty International and other human rights organisations strongly condemned Indonesia's cruel conduct toward the East Timorese. Indonesia ignored the criticism and tried to prevent that their actions in East Timor came into the open. However reports of exploitation, human rights abuses and local rebellions continued.

Japan was an important trade-partner. Approximately 53% of Indonesia's export went to Japan. The Japanese invested heavily in industries in Indonesia. Soeharto and his elite rendered Japanese entrepreneurs privileges. Indonesians, especially native businessmen, resented the Japanese exploiters. When the Japanese Prime Minister visited Jakarta in 1974 terrible riots, referred to as Malari, evolved. Mainly students and poor burned cars and buildings and looted stores that sold Japanese products. About 20,000 people gathered around the hotel of the Prime Minister and 5,000 surrounded Soeharto's palace. Soeharto's troops crushed the riots and arrested 770 civilians (1).

I.7.2 SUCCESS OF THE NEW ORDER

From about 1976 the economic Development Plans proved to be successful. The price of oil on the world market rose and money came in. Indonesia became the largest supplier of gas in the world. Annual inflation rates stayed between 10 to 20 %, which was much better than in the past. The new prosperity was ventilated in Jakarta by the erection of numerous large and modern buildings. A new middle class was established that enjoyed its recently gained wealth and was willing to accept the corruption and suppression that came along with it. Even the poor in rural areas noticed the ameliorated economic conditions.

Soeharto was able to keep good relations with the Western countries.

Muslim leaders were relieved that Soeharto's regime tolerated their existence and no longer saw Islam as a threat. Leaders of other faiths were relieved that Soeharto prevented the installation of an Islamic state.

In 1977 new parliamentary elections were held. In advance it was already clear that only Golkar could win, as Soeharto had abandoned all former political parties and created just two alternatives for Golkar: PPP and PDI.

In 1978 Soeharto was elected President for 5 years again for the 3rd time.

Corruption took place on a very large scale. Soeharto's family and his elite grew even richer. The six children of Soeharto all were in the possession of numerous enterprises.

Protests by students against corruption of the government continued. The student leader who organised the demonstrations was arrested and put in jail. A former civil servant and mystic also accused Soeharto and his clique of corruption. After collecting the signatures of prominent political and religious leaders, the mystic was arrested and imprisoned. Newspapers and magazines that wrote about Soeharto's corruption were banned.

Soeharto's regime disregarded human rights issues. Indonesia largely depended on American aid. So when Jimmy Carter, who had human rights as a priority on his agenda, became President of the USA, Indonesia decided to release political prisoners. However whilst old political prisoners were released, new political opponents were imprisoned without trial.

Communism was no longer perceived as the biggest enemy of the nation. Attention switched to radical Muslims that wanted to install an Islamic state. Discovery of an Islamic organisation that planned a Holy War (jihad) to achieve an Islamic state, resulted in the arrest of hundreds of muslims. They were held without trial. Suspicion arose that this organisation never existed, but was used by the government as an excuse to imprison political opponents.

During the Cold War it was important to the West to keep Indonesia in their camp. Indonesia was a good ally as it was anti-communist, anti-radical Islam and pro-capitalism. Western governments and enterprises profitted from doing business with Indonesia. Of course the West condemned Indonesia's human rights abuses and corruption, yet their own political and economic interests were apparently more significant than social justice in an Asian nation. Soeharto's clique was aware of the fact that their abuses would therefore be tolerated.

The achievements of the Development Plans were large. Agriculture, education and health issues were improved. Production of rice increased and Indonesia became self-sufficient. Especially in rural areas new schools were built, literacy rates increased and more and more people learned and used the national language. The use of Bahasa Indonesia in newspapers, magazines and on radio and television enforced the sense of belonging to one nation. Especially the family planning program, tolerated by the Islamic leaders, became a big success and an example for other countries that faced a population surplus.

The contrast between Java and the outer islands enhanced. Java possessed the capital city, government and largest population. The Development Plans mainly concerned the Javanese and subsequently inhabitants of outer islands felt neglected.

The economic development changed the Indonesian society. Urbanisation continued. Rural areas received electricity, schools and television. It altered and broadened the horizon of all Indonesians.

The center of Soeharto's regime was the military, referred to as "ABRI"(Armed forces of the Republic of Indonesia). ABRI was subdivided in the army, navy, airforce and police. ABRI served the corruption and abuses of the President. After passage of time, protests among mainly retired military officers increased.

In 1978 Soeharto started an indoctrination program. At schools, civil services and in companies compulsory courses, referred to as "P4", taught Indonesians the state ideology of Pancasila. Right from the start the program was ridiculed as it was so obvious that Soeharto's corrupt regime did not practice what they preached.

ABRI started a program aimed at developing, influencing and dominating rural areas and villages. Soldiers built and repaired roads, bridges and health clinics. When civilians disagreed with ABRI, the military violently stopped the critics.

When an airplane of the national airlines was hijacked by Islamic extremists, the government became more worried about Islamic opposition. Though PPP had nothing to do with the hijacking, Soeharto's regime started to harrass the political party more.

In 1982 parliamentary elections were surrounded by violence. Newspapers that reported about the violence were shut down. Also the weekly magazine that was founded by Goenawan Mohamad, one of Indonesia's most prominent intellectuals, was banned. Golkar won the election campaign.

The price of oil declined, as did Indonesia's exports. The external debt was very high by now.

Soeharto's son-in-law General Prabowo became the leader of ABRI's special forces in Irian Jaya, East Timor and Aceh. Prabowo was feared for his exceptional terror against the people of these territories. Soeharto manipulated both ABRI and Golkar. He appointed his elite in important positions and made sure that both bodies did not gain too much power. Hereby Soeharto assured that he stayed in control.

When criminal activities increased, police and military murdered about 5,000 suspects. Their bodies were dumped in public places to warn Indonesians never to join the crime scene. Soeharto denied involvement at the time, but later referred to these so called "Petrus killings" as shock therapy by the state.

In 1984 the regime demanded by law that all political, social and religious organisations acknowledged Pancasila as their only ideological basis. The reactions of Islamic organisations were diverse.The former political party NU, now a member of PPP, decided to withdraw from PPP and stop all political activities. They had enough of Soeharto's games, interference and manipulation. NU restricted its activities to religious, educational, cultural and socio-economic issues. NU accepted Pancasila as its sole foundation and started to cooperate with the government. With its loss of political power, the NU was more acceptable for the state. In this way, NU was able to

accelerate the Islamisation of Indonesia. Muhammadiyah also accepted the Pancasila as ideology, other Islamic leaders and groups did not.

Meanwhile adherence to Islam increased, mosques and prayer houses were built and its attendance rose. Worldwide Indonesia had the largest Muslim population. The enhanced devotion to Islam, also increased condemnation of immoral behaviour by the government. Violent protests against the state and cukongs broke out across Java. In Jakarta shopping malls and buildings were burned and many protestors murdered. The Buddhist temple Barabudhur near Yogyakarta was bombed. Subsequently the regime tried to stop publications about their corruption. Magazines were shut down. Many were arrested and imprisoned.

Golkar won the elections for parliament again in 1987.

Internationally Indonesia gained respect for its intervention in Vietnam and Cambodia. Communist Vietnam had invaded Cambodia. Cambodia was ruled by the horrific Khmer Rouge of Pol Pot. Most Asian countries condemned the invasion by the Vietnamese. Indonesia however had friendly relations with both countries. Indonesia respected Vietnam as it was the only other Asian country that had fought for liberation of colonial hegemony. After intervention by Indonesia an agreement was signed between Vietnam and Asia.

In 1988 Soeharto was for the 5^{th} time elected as President for another term of 5 years. Soeharto made sure he remained in power. When other men became too powerful, for instance inside ABRI, Soeharto replaced them. Also the leader of Golkar was replaced when Golkar gained too much independence.

In Asian countries economic development caused the demand for democracy. When dictator Marcos from the Phillipines had to flee, Soeharto started to fear for his position too. There had been many similarities between the two corrupt and suppressive regimes (1,4,5).

I.7.3 COLLAPSE OF THE NEW ORDER

When the Cold War ended and the Soviet Union collapsed in 1988, Western countries lost their main reason to tolerate corrupt and suppressive regimes like Soeharto's. At the same time the Indonesian middle class lost their patience with Soeharto's abusive reign. The enhanced religiosity and stronger adherence to Islam increased strive for justice and morality. Hereby condemnation of Soeharto's regime enhanced. Meanwhile the abuse of power by Soeharto, his family and confidants enlarged. Many Indonesians had only tolerated Soeharto for the economic benefits he brought. When ultimately the Asian economic crisis hit and Soeharto's reign could no longer guarantee these financial benefits, all reasons to accept his regime were gone.

Both in Aceh and East Timor the fight for independence from Indonesian rule became stronger in 1989.

In Indonesia the longing for more openness and democracy grew stronger. In response oppression by Soeharto's regime only became more intense. ABRI played a central

role in the oppression. A new method that ABRI used was letting opponents "disappear". The brutality of ABRI was strongly disliked by the Indonesian public.

Internationally Indonesia had now the reputation of being the most corrupt country in the world. The six children of Soeharto possessed large enterprises, toll roads, natural resources and became incredibly rich. They got involved with numerous corruption scandals. The cukongs controlled about 70% of the private commerce. Government, police, army and courts were corrupted.

Now that the number and devotion of Muslims increased, Soeharto tried in vain to win the support of Islamic leaders. Soeharto allowed women to wear a headscarf (jilbab) and installed better Islamic courses at schools.

The terror of ABRI was exposed to the whole world in 1991. *A funeral in East Timor turned into a demonstration against the Indonesian occupation. ABRI was not aware of the presence of a camera crew and started to shoot at the unarmed civilians. Many citizens were killed and others disappeared. The whole incident was filmed.* ABRI's misbehaviour was internationally broadcasted. From now on everybody knew about the violation of human rights in East Timor. However, the international community did not dare to condemn Soeharto's human rights abuses as long as Indonesia's economy and Soeharto's hegemony looked stable.

Soeharto was elected for his 6^{th} 5 year term as President in 1993.

In 1993 Sukarno's daughter Megawati Sukarnoputri was elected as leader of PDI. Though she did not have the charisma and intelligence of her father, she became the symbol of opposition to Soeharto's regime. As Megawati got more and more harrassed by Soeharto's regime, her popularity increased. The poor and those who longed for democracy supported Megawati. In 1996 the PDI headquarters were attacked in Jakarta. Everybody suspected that Soeharto and ABRI were behind it. In response riots broke out in Jakarta, in which many people were wounded, killed or disappeared.

The unrest in the Indonesian society increased. Religious conflicts between Muslims and Christians broke out. Labour activists created uprisings. Riots against Chinese citizens occurred. ABRI suppressed them violently.

National criticism on Soeharto's policy enhanced. Indonesian political parties and media became more critical in public. Newspapers and magazines were subsequently banned. But also within the military there were now officers who wanted Soeharto to step up. Especially retired officers started to criticize Soeharto's nepotism and abuse of power.

The international community became more critical of Soeharto's regime. Worldwide the reputation of Soeharto declined**.** Its world standing decreased even more when two East Timorese leaders received the Nobel Peace Prize in 1996. During a visit of the worlwide respected President Nelson Mandela, Soeharto was embarrassed again. The South African President namely visited an imprisoned political opponent of Soeharto.

Let us highlight one family enterprise corruption scandal. *In 1996 Indonesia wanted to manufacture a national car. Soeharto gave the contract to his son Tommy Soeharto and the Korean car company Kia. The national car was named "the Timor". However, the national car was not built in Indonesia at all, but in Korea. Taxes and duties did not have to be paid. Soeharto's family hereby received all the profits. Both Japan and America were angered by this violation of international trade rules.*

In 1997 the election campaign for Presidency ended in bloodshed. Throughout Indonesia hundreds of civilians died. It was the most violent campaign of Soeharto's rule.

In 1997 the Asian economic crisis affected Indonesia badly. Most businesses ended in bankruptcy. Unemployment increased. The middle class lost their savings. Indonesia had a very large debt. Drought decreased the rice harvest and increased the amount of forest fires. Approximately 56% of the population (113 million Indonesians) lived beneath the poverty line. The government introduced reforms, but enterprises from Soeharto's family and confidants were protected. The IMF forced Indonesia to close banks, but Soeharto reopened his own banks. The nepotism, corruption and incompetence of Soeharto's regime were clear to the world. The presidents of the United States, Germany and Japan pressed Soeharto to introduce IMF reforms. Ultimately the IMF threatened to stop loans, if proper reforms were not installed. The government however was unable to put these reforms into action.

Soeharto was elected for the 7th time as President in 1998. Habibie became his Vice-President. Habibie belonged to the confidants of Soeharto. He was a devout Muslim and a researcher. In the past Habibie had been involved in extreme losses of state enterprises. Soeharto assigned more members of his elite into significant positions. His brutal son-in-law Prabowo became head of special security forces.

Student demonstrations and riots broke out. Many students were kidnapped or killed. Prabowo was said to be responsible**.** The situation escalated when four students of the Trisakti University in Jakarta were killed. Subsequently major riots occurred throughout Indonesia. Businesses of Soeharto's family and cukongs were attacked. More than thousand citizens died in Jakarta. Hundreds of people died in fires, while they were looting shopping malls. Gang rapes took place. Foreigners were evacuated. The rich Chinese community fled from Indonesia too.

Soeharto was asked to resign. Initially Soeharto refused and declared to introduce reforms and hold new elections. This was nationally and internationally not acceptable. On 21st of May 1998 Soeharto resigned as President. Immediately Habibie became the third President of Indonesia. ABRI declared to support the new President and protect Soeharto and his family (1,6).

I.8 INDONESIA SINCE SOEHARTO (1998-present)

I.8.1 HABIBIE

Habibie had been a member of Soeharto's clique and therefore was distrusted by the national and international community. Much to everyone's surprise Habibie actually made a serious effort to introduce democratic reforms.

Habibie's political reforms created more democracy. Habibie decreased the political influence of ABRI. Political prisoners were released. New political parties were established.

The economic crisis continued. Habibie was not able to improve the economy. Not that it was realistic to expect that he could alter the tide on such a short notice. But this did not stop people from blaming Habibie's government.

Habibie assigned military officer Ghalib as head of the legal system. This angered many pro-democracy activists who did not believe a military officer would pursue Soeharto, Soeharto's elite and the cukongs. These activists were right. The pursuit of Soeharto proceeded very slowly and after one year the NGO Indonesian Corruption Watch declared that cukongs had paid Ghalib enormous sums of money. Also the investigations of the Trisakti murders, the disappeared political activists and the riots of 1998 proceeded extraordinary slowly.

Violence in the Indonesian society increased and spread throughout the nation. It did not only occur between different religious or ethnic groups, but also between different political parties. Muslims and Christians fought each other. Again the Chinese community became a target. Also the poverty caused by the economic crisis led to riots. Criminal activities enhanced too. Now that Soeharto's firm oppression did not stop the violence, it could occur on a much larger scale.

Indonesia's dissident provinces East Timor, Irian Jaya and Aceh intensified their struggle for independence from Indonesia. Habibie wanted to give East Timor independence, in contrast to most other political leaders. In 1999 a referendum on independence, sponsored by the UN, took place in East Timor. In total 98,6% of all voters took part in this referendum. Independence was desired by 78,5% of East Timorese. After this outcome pro-Indonesian guerillas and probably ABRI soldiers started to murder and destruct East Timor. Many East Timorese became refugees. Habibie and the civilian government in Jakarta had no control over the situation. The international community was outraged by the violence against the East Timorese. Habibie therefore allowed armed UN peacekeepers to guide the transition to independence in East Timor. East Timor received independence in 1999. Both Irian Jaya and Aceh were important to Indonesia for their rich natural sources. Violence increased in these provinces too and ABRI brutally suppressed it. Again the Jakarta government had no control here and ABRI ruled. Both territories faced many internal refugees. Habibie could not resolve the problems in Irian Jaya and Aceh.

Political demonstrations were held on a daily basis in Jakarta and other cities. Mainly students demanded the pursuit of Soeharto, abolishment of ABRI in politics, improved economic conditions and a new President. Sometimes protests ended in

violence and riots in which both civilians and police were killed. Especially the violence between Muslims and Christians intensified. In Jakarta a Holy War (jihad) was declared to defend Ambonese Muslims in their fight against Christians. Subsequently a bomb exploded in a mosque in Jakarta.

In June 1999 new elections were held in which Indonesians could choose their own government. Wahid became the fourth President of Indonesia and Megawati his Vice-President (1).

I.8.2 ABDURRAHMAN WAHID

Initially the Indonesians were hopeful that Wahid could truly make a difference. Despite his ill health, Wahid was determined to alter Soeharto's suppressive hierarchical and centralised system.

Wahid stimulated a pluralistic and more open society. The Chinese community was allowed to celebrate their ceremonies in public again. He renamed Irian Jaya Papua and wanted to allow a referendum for more autonomy in Aceh. However, Wahid found separation from Indonesia no option for both Aceh as well as Irian Jaya.

The government was not able to improve the economic situation. Many Indonesians faced financial hardships.

The violence between the different religious and ethnic groups continued.

The corruption and human rights abuses during Soeharto's reign were investigated and pursued more seriously. More insight was achieved in all practices that had enriched Soeharto and his elite with billions. Soeharto claimed he could not be interrogated based on ill health. Many distrusted this claim. Wahid declared that he would pardon Soeharto if he was convicted.

ABRI was reorganized. The police was now separated from the other military forces. Military officers were investigated for corruption and violation of human rights. Hereby the prominent role that ABRI had during Soeharto was taken.

The government institutions had difficulties with defining their new democratic role. Now neither the President nor the military were dominant. New structures needed to be formed to run the country in a democratic way.

Also the corrupt legal system needed rebuilding. This proved very difficult, due to corrupt judges and corrupt police. The latter were willing to pay large amounts of money. Wahid introduced decentralisation, what only enhanced the opportunities for corruption. As a result corruption increased instead of decreased in the legal system.

Corruption was the main problem in Indonesia. It was not clear whether those in power were able and willing to investigate, punish and eradicate corruption. It was even not clear if those in power would resist the opportunities for corruption themselves.

In July 2001 Wahid was replaced by Megawati as fifth President of Indonesia (1).

I.8.3 MEGAWATI SUKARNOPUTRI

When Megawati Sukarnoputri came to power, she took over a nation beset by economic difficulties and sectarian violence.

As the daughter of former president Sukarno, many Indonesians hoped she would be the answer to all their problems.

Megawati did bring more political stability and she attended a ceremony in East Timor in 2002 to mark its independence from Indonesia.

However, her presidency was characterized by rampant corruption, unemployment and an increasing threat from Islamic militants. In 2002 the Bali bomb attacks resulted in more than 200 deaths, mainly Australian tourists. Megawati was criticized that she had failed to make progress in the fight against corruption, terrorism and regional militancy durin her presidency.

In October 2004 Megawati Sukarnoputri was replaced by Susilo Bambang Yudhoyono as sixth President of Indonesia (7-9)

I.8.4 SUSILO BAMBANG YUDHOYONO

Susilo Bambang Yudhoyono started his carreer as military commander and was Chief of Territorial Affairs during East Timor's violent transition to independence. In 2000 Yudhoyono changed to politics and joined the government of president Abdurrahman Wahid. Yudhoyono initially became minister for mines and later minister for security and political affairs.

When president Abdurrahman Wahid faced impeachment, he asked Yudhoyono to declare a state of emergency. Yudhoyono refused and was immediately fired by president Abdurrahman Wahid.

During the presidency of Megawati Sukarnoputri, Yudhoyono was senior political and security minister and played a leading role in the aftermath of the Bali bombings. However, Yudhoyono resigned after a public conflict with Megawati and her husband.

This gave Yudhoyono the reputation of a man of principle and integrity, who would sacrifice his own ambitions for the values he believes in.

Susilo Bambang Yudhoyono won the elections in 2004 with his strong communication skills and image of a firm leader in times of crisis.

President Yudhoyono approved elaborate anti-corruption investigations, concluded a peace agreement with rebel leaders in Aceh and attracted international investment. But critics say that president Yudhoyono, known as "the thinking general" has been indecisive and considers all views and opinions for too long before making up his mind (10).

Do not ridicule, regret or condemn human conduct but understand

Spinoza

II. JAVANESE ETHICS

Public life in Java is dominated by two principles of great significance: the **principle of conflict avoidance** and the **principle of respect**.

The first principle prescribes all Javanese to avoid confrontation in each and every situation. The second principle demands the expression of respect in speech and behaviour toward all those who hold higher positions in society. These two principles determine every form of Javanese interaction. They are taught during childhood. Javanese citizens are always consciously aware that the environment expects their conduct to conform both principles (11).

II.1 THE RUKUN OR CONFLICT AVOIDANCE PRINCIPLE

II.1.1 DEFINITION OF RUKUN

The aim of the principle of conflict avoidance is the **maintenance of social harmony or "rukun"**. Rukun is the ideal situation that Javanese wish to see in all relationships and in the entire society: all involved are at peace with each other.

It is important to note that it is not about creating social harmony, but about not disturbing the existing situation. The principle is therefore passive in nature: avoiding conflict.

Rukun also refers to a mode of behaviour. To act according to rukun, means to give the impression of perfectly balanced social relationships and to suppress all signs of tension. All persons should interact peacefully and remove potentially antagonistic elements.

The rukun principle does not concern internal attitudes. It only concerns the observable expression of public relationships and outward harmony in society (11).

II.1.2 CONDUCT OF RUKUN

Rukun can be threatened by conflicts and emotions;

- **Conflicts.**
  Conflicts can arise when there are opposing interests. Private gains should therefore be set aside in order to maintain social harmony. Individual initiative will be judged negatively, because innovations will change the balance of social forces and can thereby lead to conflict. People should always work together in a group. Taking up an opposed stand, even if it could benefit the group, is seen as improper. Personal ambitions should never be expressed.

- **Emotions.**
  Emotions can also raise conflicts. Norms of conduct have therefore been developed in Java that try to prevent coming into the open of emotions.

Javanese must act in a controlled manner; appearing relaxed and calm at all times, speaking in an emotionless voice, and never showing surprise or excitement. Javanese citizens should always avoid to surprise or shock others. One should always take into consideration everyone's reactions and act in such a way that no confrontation or conflict can emerge.

Javanese always have to avoid questions that need a simple "yes" or "no" as response, thereby forcing others to take a confrontative position. Typical replies therefore are: "according to me" or "maybe".

The public expression of feelings and thoughts is viewed as very bad taste. Impulsiveness and spontaneity are considered as lack of development. Better do nothing than cause unrest. Loss of self-control is seen as a shame.

In situations where confrontative interests are present, one should behave carefully. Requests should never be openly rejected or refused. The answer will always be a polite "yes" and never a direct "no". One should then afterwards determine whether it was a true "yes", a polite reply without commitment or a concealed "no".

A highly appreciated trait in Java is the capacity to conversate about unpleasant issues in an indirect manner. Bluntness is disliked. Another prized quality is "ethok-ethok"; never showing true feelings. This holds especially truth for negative feelings. Even when grieving, one must smile. Even when disliked people enter your home, one should show happiness to have them as guests. Likewise, strong positive feelings should also be disguised.

Rukun also demands that relatives, though distant and detested, are supported when necessary. This is namely less worse than an open conflict or the danger of being viewed as a person who is not rukun with the family (11).

II.1.3 TEACHING OF RUKUN

Javanese learn the conduct of rukun during childhood. Two phases can be distinguished in the social disciplining;

First phase.
The first phase takes approximately until the fifth year and is characterized by **intense tension-free family relationships.** The child receives love and attention. It is always in physical contact with its relatives and never left alone. Frustrations and excitements are avoided. It is remarkable that the Javanese baby is not allowed to crawl as this is considered dangerous; evil spirits could harm the child through the ground. Exploration and discovering the surroundings are excluded. The family prevents shocks and dangers.

During this phase there are two methods of teaching social discipline;

- **Gentle repetition.** The child observes and imitates the conduct of its relatives. Naughtiness and cleansing training are gently dealt with. Parents never

respond emotionally or angry as children cannot understand reason yet and thus cannot control drives and emotions.

- **Threat of forces outside the family.** Obedience is acquired through the threat of external forces (evil spirits, dogs or strangers). Parental punishment or warnings are absent. The world outside is considered dangerous. The child hereby depends largely on his family and becomes very sensitive to even the smallest reactions of outsiders.

Second phase.
The second phase starts at about the age of five years. It is now expected that the child understands reason. The child is taught proper conduct through **remarks about the disapproval of the outside world.** Thus not the mother's disapproval is mentioned, but what others might think about such behaviour. Non-conformist conduct will be penalized. The child learns to feel embarrassed, ashamed and guilty in front of outsiders. It learns, for instance, to feel ashamed when expressing feelings openly.

Once Javanese reach adulthood, they accept that their well-being depends on integration into the group. Dependence is regarded as positive. Conduct that deviates from the rukun principle counters strong psychological resistance. They avoid, at all costs, disturbance of social harmony.

Social harmony in a group brings peace and satisfaction. Social harmony guarantees absence of negative feelings and gives security. Decisions or responsibility do not have to be taken alone. Javanese can encounter the unkind world as a team. Custom and etiquette will keep the social harmony safe in any occasion (4,11,12).

II.1.4 RUKUN DOES NOT CONCERN INTERNAL ATTITUDE

The rukun principle is a principle of social behaviour, not of internal attitude. It is important to act in such a way that the observable surface remains peaceful. Rukun does not relate to a condition of mind: **inner attitudes do not have to correspond with the outward conduct of rukun.** What a person thinks is a private matter. Rukun has nothing to do with an ideal of neglecting one's personal interests in favour of those of the group. It is thus not a matter of altruism versus egoism. The Javanese do perceive themselves as individuals, with their own sorrows, rights and goals. Within the limits of rukun, they try to realize personal interests. The rukun principle thus only concerns outward behaviour and therefore it is not a moral principle.

The Javanese have a number of indirect ways of expressing inner disagreement;
- Spatial separation. To simply walk away from trouble is an easy manner to cope with conflict.
- Not speaking with each other for given periods; days, weeks or an entire life.
- Doing nothing at all.

However,also Javanese have their limits of acceptance and prevailing social harmony. When these limits are exceeded, a highly emotional confrontation occurs out of proportion with the occasion. This does not clear the air, but destroys the relationship. It is a complete and highly embarrassing breakdown of the rukun principle (11).

II.2 THE RESPECT PRINCIPLE

The principle of respect demands that **every person, in speech and behaviour, has to show appropiate respect to those who hold higher positions in society.** It is based on the idea that all interactions in public life are organized in a hierarchical order. This hierarchy is good in itself. Everyone is morally obliged to preserve and express respect to this hierarchy. This belief is also based on the ideal of a perfectly organized society, in which each individual understands his position in the social order and helps to maintain the harmonious whole. The social hierarchical order will remain safe as long as everyone is satisfied with his place in it and accepts his destiny. An individual should therefore not be ambitious or competitive.

Awareness of social hierarchy dominates the entire Javanese public life. In the Javanese language it is even not possible to talk to someone without revealing how one views one's own position in the hierarchy compared to his.

Javanese are taught the principle of respect from childhood. They learn three main feelings associated with showing respect, namely wedi, isin and sungkan:

- **Wedi** means to feel afraid of persons deserving respect. A child will be praised when it shows fear of older people or strangers. This polite manner is built in by warnings against evil powers outside the family.
- **Isin** means to feel ashamed, shy and embarrassed. Children are trained consciously to feel isin when they behave incorrect in front of people outside the closest family. Protection against feelings of isin is provided by etiquette of words and gestures. This gives the security that one behaves right. The fear of isin feelings is for Javanese one of the strongest motivations for socially correct behaviour.
- **Sungkan** means a positive feeling of shyness which one experiences in the presence of superiors. This feeling does not have to be avoided.

The incorporation of these feelings is the sign of a mature Javanese personality.

Showing respect is based on the idea that people behave best when they honor and serve superior authorities and elders. Franz Magnis-Suseno, a professor in social philosophy and ethics, explains it this way: "**Subordinates should not measure their superiors against moral guidelines, and should not criticize them or call them to acknowledge their responsibilities.** The opposite is the case: the actual behaviour of the superior is justified through his position and becomes the standard which the subordinate strives to imitate" (11).
This conduct is considered a main cause for corruption and limited awareness of responsibilities in Java. There is no real communication between superiors and subordinates. The superior gives instructions and the subordinate reports. The content of the reports must correspond to the expectations of superiors. These reports are called **"**ketjap reports" (laporan kecap), as they are flavoured according to the taste of the superior. The report tells what the superior wants to be told.

Let us give an example mentioned by professor Magnis-Suseno:

> *"A representative of the government from the city visits the village assembly. Of course the high ranking guest is treated with respect. But this is no guarantee that his instruction will be executed. Direct criticism of his*

suggestions is not possible. If the official does not try to get the real and honest consent of the villagers, the instruction will be either so modified as to correspond to the wishes of the villagers, or not followed at all" (11).

Like the principle of conflict avoidance also **the principle of respect has nothing to do with inner attitudes, but only with outward behaviour.** Disrespectful conduct harms the principle of respect, but disobedience does not. It is not necessary to feel respect for superiors as long as the outward conduct shows respect. In Javanese relationships the sincerity of the relationship is not important.

The principle of respect must not be mistaken for obedience to execute any command. Subordinates may listen respectfully and appear to agree with the superior's order, but this is no guarantee that it will be executed. Proposals which oppose against the interests of subordinates, or are regarded as improper, will either be ignored or boycotted. In this instance Javanese blame the superior. A good superior should find out what his subordinates want through dialogue. He is expected to only give a command when he knows that the subordinate truly agrees and ready to put it into action (11).

II.3 SOCIAL HARMONY RESTRICTS MORAL PRINCIPLES

The principles of conflict avoidance and respect have priority over all other principles. They set the limits for all behaviour. Ethical considerations are subordinate to these dominant principles. Thus the principle of harmony restricts an individual's duty to act on his own judgement and take responsibility. Social harmony should never be disrupted by a person's sympathy for people in need, responsibility for a task or violation of moral principles. Even an appeal to a person's moral conscience does not justify him to harm the harmony principle. For example, the moral obligation to offer help to those in need, does not give an individual the right to thereby raise conflict.

The question is: would Javanese society always condemn conflict-prone behaviour that is based on convictions of conscience, moral norms, responsibility and duty?

Let us look at the following example given by professor Magnis-Suseno:

"Suppose I obtained information that the chief of a village has used development funds for his own use. I feel obliged to expose this, not only because of its illegal nature, but also because only when I do this there is a chance to bring benefit to the poorest families in the village. Also in Western ethics, I would not be justified in making public accusations on these grounds alone. I am morally obliged to consider all other relevant factors, such as the situation of the chief or the preservation of the village peace. Only after weighing all factors, I may reach a morally justified decision and act upon it. But in Java the harmony principle demands that, no matter what I judge morally right after all these considerations, I may not carry it out as it disturbs social harmony. This is true even when I judge that conflict is the lesser evil for society" (11).

The principles of social harmony and respect are given absolute priority. This restricts the validity of other moral principles. Members of society have no right to form their own judgement about their moral duty and responsibility under certain circumstances. An individual thus has limited moral autonomy and limited moral responsibility (11).

II.4 DIFFERENT PERSPECTIVE ON GOOD AND EVIL

The limited validity of moral norms affects also the difference between good and evil. The idea of evil is based on the will. Evil is the will to behave in a morally wrong manner.

In Western society the norms of morally right actions are regarded as absolutely binding. A person who deliberately acts in a morally wrong way, violates his absolute duty. His behaviour is evil. Westerners have the absolute duty to act in a morally right manner and one should never consciously violate moral norms. Evil should absolutely never occur.

In Javanese ethics this dichotomy of good and evil is softened in two ways:

- **Javanese do not think in terms of good and evil, but in terms of wise and foolish**. They do not associate morally wrong behaviour with an evil will, but rather with "faulty understanding". Such a person has not yet reached full understanding and insight. This person is not considered evil, but spiritually underdeveloped and immature. He is not an object of moral aversion, but of regret and pity. "Faulty understanding" does not mean ignorance of moral norms. The individual knows the rules and superficially understands how he should act, but does not do so because, for instance, he seeks personal advantage. Such a person is not evil, but foolish. Only narrow-minded people can become irritated or excited by foolish behaviour. One can never force a person to gain more insight and understanding. One can only hope that one day he will come to understand. It is noteworthy that there is no word for "evil" in the Javanese language.

- **Javanese do not think that evil should never occur**. They believe that a connection between social and cosmic harmony exists. The cosmos as a whole is full of tension and secrecy in which good and dark forces cooperate. These dark forces are necessary for the preservation of balance. Cosmic harmony can only be maintained when all elements of the universe take up their predestined positions. In the same way, the Javanese belief that there are individuals necessary in society with evil and antagonistic roles to maintain balance. Social harmony can only be preserved when all individuals fulfil their specific duties, determined by their lot and position in society.

In practice Javanese are not blind to internal motives that form actions. According to Javanese ethics they should judge people as wise or foolish, but in real life they do differentiate between good and evil men, between people worthy of trust and those not. However, right or wrong in Javanese ethics is not related to the internal attitude or will, but to the outcome of conduct: harmony (11).

II.5 ALUS AND KASAR

We have seen that Javanese morality is based on maintaining social and cosmic harmony. Our conduct is right when it advances harmony and wrong when it disrupts harmony. Javanese judge all phenomena in their environment with two opposing aesthetic categories; “alus” and “kasar”.

Alus is a sign of harmony. Anything “alus” is beautiful by definition. Whatever is beautiful, is good, because it actualizes harmony. If society is in harmony everything happens smoothly and quietly. Alus thus means soft, smooth, elegant, polite etc. A person is alus if he controls his outward behaviour. Alus is a sign of strength. The more alus something is, the better and more right it is.

Kasar is a sign of lack of harmony. Anything “kasar” is ugly. A disturbance of harmony is ugly and therefore bad. Kasar means coarse, rude, blunt, independent, direct, critical etc. A person is kasar if he is lacking self-control and is immature. Kasar is a sign of weakness. The more kasar something is, the worse and more regrettable.

Moral actions are measured by the degree to which they are alus or kasar or make a condition more alus or kasar (4,11).

Anyone who does not know the power of the word cannot know the people

Confucius

III. JAVANESE LANGUAGE

Like Javanese society, also Javanese language acknowledges a strict **hierarchy**. It is not possible in Javanese language to speak to someone without revealing how you see your position in society in relation to his.

In Java it is important that every person knows and accepts his place in society. A true Javanese is always consciously aware of his position in the social hierarchy compared to others. It is essential to express this awareness in a combination of language and behavior. Only by doing this a Javanese shows respect and maintains social harmony.

The Javanese language has the most extensive use of **speech levels** of all known languages in the world. Javanese use five speech levels. This means that they have **five types of vocabulary classes.** The specific vocabulary class you chose, indicates the degree of respect you pay to a person. This sophisticated language dates back to a very old and highly civilized culture at the Javanese courts.

The five speech levels consist of three main levels and two additive levels. The three main levels are:

- **High Javanese** or **Krama**.
  This is the highest speech level that is used to all people who have either a higher position in society or are older. Krama is a highly refined, distant and polite speech. It consists not only of about thousand words, but also has a different grammar than the low Javanese speech level.

  High Javanese is also referred to as "**the mask**", as it does not show the true internal attitude. It shows respect, avoids conflict and preserves social harmony. In High Javanese it is linguistically simply not possible to insult somebody or express emotions.

- **Middle Javanese** or **Krama madya**.
  This speech level is a combination of high and low Javanese. It is a rather polite and formal speech that is used for familiar persons with whom one is not intimate. Middle Javanese is not only a mixture of high and low Javanese, but also has 35 specific words.

- **Low Javanese** or **Ngoko**.
  This lowest speech level is considered to be harsh and direct. It shows no respect and can only be used with very close friends or relatives. It is the base language and when a word does not exist in a higher level one is allowed to use the low Javanese word for it, without offending the person spoken to.

  Low Javanese is the first language that children learn. It is also used for thinking, talking to oneself and showing emotions.

There are two other speech levels that you can add to these three main levels, in order to show extra respect at the chosen main level:

- **Humble Javanese** or **Krama andhap**.
  This speech level consists of approximately thirty words, which show extra respect by humbling the speaker.

- **High Krama** or **Krama inggil**.
  Also this speech level contains about thirty words, which show extra respect by honoring the addressee.

In daily life, Javanese tend to simplify these five speech levels to two languages: "**basa**" or "**non-basa**". Non-basa refers to low Javanese, and basa to all the other polite speech levels.

It is important to know that Javanese are expected to avoid conflicts and maintain social harmony. Therefore both their behavior and language have to be controlled. They are not allowed to say, what they think. This means that in Javanese language **many words are not spoken**. Keeping silent is essential. Thus both proper choice of words and **proper silences** characterize the Javanese language (11,13).

For a long time now, the authorities, in their ivory tower of arrogance, have tried to force us "not to see what we did see, and to see what we did not see". We were supposed to see the "unseeable", and they believed that it was possible to completely control the people's perceptions and thoughts. They demanded total conformity. This coercion to see the unseeable is to discourage people from independent thinking. If successful, this intentional misleading of the people might result in their uncritical obedience. The ultimate outcome would be the free play of power, in which the ruler is the law, instead of a constitutional state in which the law is the ruler.

Mochtar Buchori

IV. A CRITICAL VIEW ON INDONESIA BY SOCIAL SCIENTISTS AND COMMENTATORS

In the following chapter a critical view on Indonesia by leading social scientists and commentators will be presented. The views expressed in this chapter may not necessarily comply with mine.

IV.1 PANCASILA AND LEADERSHIP

The **Pancasila** is the **state ideology** that prescribes how the nation and its citizens should behave to reach a perfect society. It was created by the fighters for freedom of Dutch rule. The concept was influenced by their Western education during colonization. In 1984 during the reign of Soeharto the Pancasila became by law the ideological basis of every political, social or religious organization.

The Pancasila mentions the **five basic principles** of the **Republic of Indonesia**: "belief in God, just and civilized humanism, unity of Indonesia, democracy guided by the wisdom of representatives and social justice for all Indonesians" (4).

In the Pancasila the **nation is seen as a family**. Like family life, the state should also be guided by two basic principles: the principle of showing respect and the principle of conflict avoidance or social harmony.

Indonesian family life has a strict **hierarchy**. Parents must care for, guide and teach their children. Children should respect, honour, accept, follow and obey their parents. According to the Pancasila, the state is a big family, in which the leader of the state operates as a father. **The leader guides and his subordinates must honor, accept and follow**.

Let us look more closely at some illustrative texts of the Pancasila:

> *"The executive of the government is the president of the Republic of Indonesia. The presidency is a high office that is occupied by a national who is selected, praiseworthy, reliable and respected."*
>
> *"Indonesian nationals are obliged to submit and obey all the regulations that emanate from the government. We are also obliged to respect the officials who carry out the administration."*
>
> *"We believe that if all Indonesian nationals fulfil their obligations to the state, the state shall also satisfy the rights of each individual. The good Indonesian national will always give precedence to his obligation over his rights." (4)*

Like in a family, **conflicts should be avoided in a state**. Open conflicts, protests or criticism disturb social harmony. It shows the weakness of a leader who is apparently

not able to control his subordinates. Inhabitants with a critical attitude toward their leaders are viewed as “rebellious”. Demonstration of students or workers is not seen as a request for dialogue. It disgraces both the leader and the protestors and therefore it must be suppressed. In Indonesia conflicts cannot be solved, but only suppressed and terminated. Solving a conflict would mean giving in and thus losing.

All Indonesian pupils have to learn the Pancasila ideology until the end of high school. This Pancasila Moral Education emphasizes the subordination of individual interests to the interests of the state.

Superficially the Pancasila leadership could look like the restoration of traditional Javanese hierarchical relationships. But in reality this impression is false. Both leadership and practice of justice have lost their moral values (1,4).

IV.2 DEMOCRACY

Though one of the five basic principles of the Pancasila is democracy, the state ideology describes **paternalism**. Operating in a fatherly manner denies people the chance of contributing to society and taking responsibility for their actions. It denies equality. This is undemocratic.

Paternalistic leadership has led to **abuse of power, corruption and social injustice**. This is very clear in the public service, where civil servants behave tyrannical to the public. The powerless cannot influence those in power.

In the Indonesian political culture the **leaders set the rules**. Disagreement, criticism or discussion is seen as opposition and disturbance of social harmony. This cannot be tolerated and has to be suppressed with intimidation or if necessary with violence. In a democracy, policy is determined after debate, in which opinions are exchanged and critically compared. In Indonesia the leaders express their opinion first, and this will automatically become the collective opinion. The power of the leaders cannot be questioned.

The **public has become cynical** toward the politicians, who lack integrity and morality, abuse power, lie and deny undeniable facts.

According to Mochtar Buchori, one of the most respected commentators on Indonesia, there is no democracy in Indonesia, but colonial exploitation in which only the actors have changed and not the principles: the former Dutch colonizers are replaced by native colonizers now (5).

IV.3 EDUCATION

According to Mochtar Buchori characteristics of the Indonesian educational system are: “**political interference**, ideological indoctrination, bureaucratic dogmatism, weird curricula, low quality teachers and an anti-intellectual climate” (5).

As the government disapproves of curiosity and intellectual development, the educational system creates an obedient public that will swallow the opinion of the rulers. This is easy for the leaders to control.

Manipulation by the government also occurs in academic life where the critical capacity of students is deliberately not being developed. The knowledge of foreign languages is generally insufficient and hereby university students merely have to rely on the scarce Indonesian research literature. They hardly have access to world literature. This keeps them ignorant of, for instance, history, humanism and social criticism.

Schools, universities and students generally do not protest. Maybe they are afraid, but more likely the government is very successful in creating **ignorance and obedience**.

Goenawan Mohamad, one of Indonesia's most prominent intellectuals and a well-known columnist and commentator on Indonesia, describes it:

> "*We are living in a time*
> *when to think is a strange,*
> *even dangerous activity"(5).*

The quality of education is still declining. Mochtar Buchori thinks that the only way to accomplish a genuine democracy is through building up a good educational system (1,5).

IV.4 CONSUMER SOCIETY

Soeharto decided that society should forget the past and look at the future: **economic development** became most important. The military forced subordinates to construct roads, buildings and work on agricultural intensification. Money soon came in, but only a few grew very rich, and most people felt left behind. Apparently development was an unfair process from which only few profited.

It was a time of rapid changes and **urbanization**. Society thus became more city life-centred with its fixation on the future, **individualism** and the foreign Western example.

Advertisements told people what consumer goods they should buy to distinguish themselves from others. Also nowadays, the media teaches people what to want and how to live. In the past this was taught by tradition. As **consumerism** has become the new standard of status and respectability, money has become extremely important.

With individualism and consumerism being promoted, citizens end up caring only for themselves. How to make as much money as possible becomes their main drive, regardless of the consequences to others. Greed is a common phenomenon. Indonesia has turned into a money-dominated society (4,5).

IV.5 RELIGION

When moral values in society have vanished and money rules, religion becomes stronger. People search for a **moral identity**.

Niels Mulder is a professor in cultural anthropology and explains it as follows:

> *"By stressing dutifulness and obedience, and frustrating the possibility of active, responsible citizenship, the state promotes individual-centeredness and moral vacuity. These prove to be healthy matrices to foster the blatant cult of money and the thriving of Islam"(5).*

Religion has spread rapidly in Indonesia. This phenomenon, called **Islamization**, is common in modernizing environments.

Islam is in Indonesia the only way one can express political, social, cultural and moral frustrations. Through religion one can, for example, react against the loss of morality, abuse of power, corruption, individualism and Western consumer culture.

Especially the middle class of society finds religion appealing.

Islamization can be seen as a **reaction against modernity, development and materialism**. Religion would probably not grow so strong, if these phenomena were not accompanied by benefit of a few, suffering of most and immoral greed (4,5).

IV.6 THE PRESS

According to the officials, the press in Indonesia is "free and responsible". This means that it must follow a narrow path between self- and official **censorship**. Certain subjects are therefore absent. Indonesian newspapers are not allowed to write about politics or politicians. The leaders decide and therefore there are no problems or conflicts to write about.

Most news is neutral. Nevertheless, critical opinion is being produced, not so much by the regular press, but more by certain magazines and columnists. Writers have invented ways to say a lot without openly offending anybody. Sometimes sensitive issues are told about foreign countries, but the parallels with Indonesia are clear.

Investigative journalism is rare and dangerous. After publishing a sensitive report the newspaper usually receives a phone call that they cannot "confuse and stir up society", they should behave "free and responsible".

Newspapers are allowed to write about courts and justice, as this is considered irrelevant. So pages are filled with stories of corruption scandals (5).

IV.7 NATIONAL CRISIS

> *"What emanates from official quarters concerns statements and ideas without morals, without a soul. Does this mean that all our officials are indeed without conscience? No, it is not that bad, but they know that they cannot change the system: they know that refusal means dismissal. When it takes heroism to act morally, a country is really in very bad shape, it is pitiable"(5).*

These are words from Mochtar Buchori.

The founders of the Republic of Indonesia had the ideal of building an independent humane, democratic society. But present society turns out to be characterized by abuse of power, indoctrination, an immense gap between the rich and poor, social injustice, violence, lies, immorality, dishonest courts and a corrupt public service.

The present state has been successful in enriching the privileged and suppressing the poor, creating ignorance and obedience among young generations, breeding cynicism and public distrust of politicians and civil servants. Indonesians feel unsafe.

But those in power do not seem to care (5).

When fighting injustice
do you fight to punish
or do you fight to change

Gandhi

V. CORRUPTION

Indonesia has the reputation of being one of the most corrupt countries in the world. In Indonesia corruption exists at all levels and dominates the entire society. It is public knowledge that not only government, politics, courts, police, immigration, business and universities are corrupt, but also hospitals are known for this phenomenon. Corruption has infiltrated Indonesia completely and is called the national cancer.

Therefore it is essential for any developing project in Indonesia to be aware of this problem. Trying to understand it, may help design measurements to limit its proportions.

V.1 STUDYING CORRUPTION

When doing research on corruption, the usual social scientific investigation techniques (like the interview, questionnaire and statistical analysis) cannot be applied, because corruption is viewed as illegal and shady. A researcher can therefore only observe and attempt to collect sufficient and reliable data. It is important to realize one will never be able to reveal, all there is to reveal.

The scientist on corruption needs background information to offer any insight beyond that what is clear. He or she should not only know the circumstances of an institution, but also the history, culture and language of a society (5,14).

V.2 DEFINITION OF CORRUPTION

Corruption can be defined as: “the abuse of trust and the intentional violation of duty, motivated by gaining personal advantage, from a party in need of a decision by a public servant” (14).

Professor Syed Hussein Alatas, who has studied the problem of corruption for many years, mentions that corruption consists of three types of phenomena:

- **Bribery** is the illegal demand of extra money for the usage of public services.
- **Extortion** is the ordering of gifts and favours when executing public duties or using funds for private purposes.
- **Nepotism** is the assignment of family members or (political) friends to civil services regardless of their capacities and effects on public wellfare.

These three phenomena have the following in common: “the subordination of public interests to private aims. It is accompanied by secrecy, betrayal, deception, suppression, exploitation, inequality and a tremendous disregard for any consequence suffered by the civilians” (5,14-16).

We can differentiate corruption from other forms of related but distinctive conduct, such as criminal behaviour and maladministration or mismanagement. Their results

also harm the public. As corruption develops in intensity, the association of corruption and crime becomes stronger.

Professor Syed Hussein Alatas acknowledges the next obligatory characteristics of corruption. These traits all have to be present in order to classify conduct as corrupt:

- Corruption involves more than one individual.
- Any act of corruption is surrounded with secrecy.
- Corruption takes mutual obligation and mutual benefit.
- Corruptors camouflage their transactions by some kind of justification.
- Those involved in corruption are capable to influence definite decisions.
- Corruption involves deception.
- Corruption is a betrayal of trust.
- The conduct of corruptors is characterized by contradictory dualism. When a corruptor is bribed to perform his job, the act is a function of both his profession and his self-interest.
- Duty and responsibility are violated in corruption.
- In corruption common interest is deliberately subordinated to personal interest (14).

In a corrupt nation, there is an official and unofficial procedure for almost every activity of government institutions. For example, not only licences and permits can be obtained illegally, but also admittance to the university does not have to be based on test results.

In corruption three types of participants can be distinguished:

- **Corruptor.** This is the perpetrator of a corrupt act**.**
- **Partner in corruption.** This is a person who deliberately bribes to receive a favoured treatment and thereby harms the rights of other people. *For instance, when a salesman willingly bribes a public servant to reach a business deal.*
- **Victim of corruption.** This is an individual who unwillingly bribes to receive a right. In this case injustice is only done to this individual and not toward other people. *For example, when an individual has to bribe to receive a passport* (14).

V.3 TIDAL CORRUPTION

Corruption is an age-old problem and all human societies are to some extent affected by it. No country can be completely free of isolated petty corruption that is usually restricted to the upper class in government and business. However, the real problem is corruption that dominates the entire life, which is the case in Indonesia.

In Indonesia the government institutions are seriously infected by corruption from top to bottom. Almost nothing can be achieved without graft or influential connection. This kind of corruption is known as “tidal” corruption. Like a tide, corruption rises and immerses all it encounters. This tidal corruption increases very rapidly the number of perpetrators: more and more people become corrupt. Thus corruption stimulates further development of greater corruption and so on.

Tidal corruption paralyses the governmental administration by creating an increasing number of rules and regulations for which one can ask bribes, causing delays. It also kills the enthusiasm of honest civil servants. It leads to a serious neglect of the public welfare.

Usually the succession from the stage of isolated petty corruption to the stage of tidal corruption starts with the upper class. After passage of time, in which this class enriched themselves with corrupt practices, society will feel the effect. The government revenue decreases, the currency devaluates and prices rise. Out of need and lack of security people from lower classes will follow their example and become corrupt too. So when corruption becomes widespread in the civil service or is used by the nurse in the hospital, it is usually the effect of previous corruption at the top. Certainly, corruption can favour an individual, but its influence on society as a whole is destructive. For every person that gains a profit, there are hundreds hurt. The general economic hardship is thus generated by corruption of economically higher classes.

The results of full-grown corruption are evident. In Indonesia, no political party has ever denied the existence of widespread corruption. The effects are too clear to hide.

Indonesia has reached the stage that corruption becomes self-destructive. It is now not only a problem to the common man, but also to those practising it. The corrupt do not want their ill-gotten wealth to be threatened by corruption. Ultimately this widespread corruption can cause a bitterness that can lead to a crisis, revolution or civil war (5,14,17-19).

V.4 CAUSES OF CORRUPTION

Throughout history, corruption has intermittently recurred.

The Chinese reformer Wang An Shih, tried to eradicate corruption during the 11th century. He mentioned two sources of corruption**:** bad laws and bad men. He recognized two groups of people: a group with high moral integrity and a group without. Danger of corruption arises when the latter group becomes in power of the state. Their passion for luxurious living then emerges in a corrupt government. The only two remedies against corruption, he believed, were leaders of high moral integrity and rational and efficient laws.

Indonesian history shows that corruption was already present in ancient times. However, after World War II and the gain of independence from Dutch rule an outburst of corruption occurred. This drastic post-war outburst of corruption is seen in most Asian countries which were liberated from Western rule. The magnitude of the problem of corruption is still increasing. A current view on the causes of corruption identifies the following factors:

<u>Before World War II</u>:

- Colonialism. The Dutch occupiers had forced Indonesian citizens to submit themselves to the rules and will of an alien Dutch government. Disobedience was not tolerated and punished by the colonizers. This created fear among Indonesians.

The colonizers of the Netherlands were known for their exploitation, corruption and disregard for the wellfare of the native inhabitants. In order to survive Indonesians had to keep criticism to themselves and be silent. The will to fight corruption was therefore hardly present.

During World War II:

- Widespread corruption emerged in this short period.

Directly after World War II and gain of independence**:**

- The administration increased tremendously with many new rules, regulations, contracts, licenses and permits.
- This increase in economic activity of the government provided new opportunities for corruption at a larger scale.
- Assignment at various levels of powerholders with low moral caliber.
- The leaders, who fought for independence, were inexperienced in setting-up an efficient government.
- The abuse and manipulation of corrupt foreign businessmen and industrialists.

After World War II and gain of independence:

- The absence or lack of moral leadership in crucial posts, able to inspire and influence behaviour against corruption.
- Religious and ethical messages are weak. Materialism dominates.
- Lack of education. Only a minority is critically aware of the problem of corruption.
- Poverty. Poverty encourages the get-rich-quick trend through corruption.
- Absence of severe punishment. As the judges in the court are also corrupt, grafts rule there too. Without serious punishment corruptors continue their practices fearlessly and others are encouraged to illegally gain wealth. As complaints against the corruptors are not properly dealt with, the public confidence is lost. Cynicism remains that the government is against corruption, but not against corrupt persons with power, influence, money and protection.
- Absence of environment with anti-corrupt behaviour. In society the public will to fight corruption is weak. The ordinary citizen is hesitant to report corruption cases, not only out of fear of reprisal, but also because the convicts are mildly punished and able to resume corruption afterwards. This public hesitation is understandable as the authorities are associated with negligence, indifference, inefficiency, decadence and corruption. People who grew up in this psychological climate are more prone to tolerate than resist corruption.
- Structure of government is not capable to control or stop corruption.
- Radical change. Whenever a society faces a dramatic transition, like the industrialization process, corruption can emerge.
- The condition of society. A corrupt bureaucracy represents the state the whole nation is in.

By themselves these factors cannot explain the practice of corruption. The importance of these factors lies in their combination (1,4,5,14).

V.5 PSYCHOLOGY OF CORRUPTION

In a corrupt nation, corruption enters into the lives of its citizens from childhood. Already in elementary school infants face its destructive effects. Going through life, they have to experience exploitation at frequent intervals. Whole generations are raised under its shadow. An Indian observer describes it like this: *"Corruption is the largest single element to be found most in India. All roads, from the maternity hospital to the crematorium, smell of corruption. No individual is free from it, no area can be found where corruption is not a ritual"* (14). Many find these conditions unbearable, but only a few can migrate. The majority is stuck in a corrupt society.

Tidal corruption in a country affects the psychology of its population in several ways:

- Tidal corruption generates social injustice and thereby a **sense of insecurity.** Insecurity emerges from an immoral social environment: those in power lack respect for moral values and also the law does not protect the individual.

  In a country in which most struggle for a daily living, corruption can have inhumane consequences. *Consider selling donated food supplies in times of famine on black markets. Consider not treating patients of serious diseases with provided drugs. Consider the abuse of funds for development projects* (5,14,15,18).

- It also causes a **pessimistic attitude.** Honesty and hard work do not result in security and welfare.

- Corruption and abuse of power becomes like the weather: unpredictable and uncontrollable. People feel **powerless** and become **passive**.

Professor Syed Hussein Alatas describes the abuse of power in a hospital as follows:

"The doctor insisted on a bribe. Let us imagine ourselves in such a situation. How would we feel? We become the object of a cruel and overpowering exploitation. We are in the most dependent situation, in need of help. Yet what we get is a cruel exploitation. We have to accept it for there is no other way out. The sense of disgust, anger, disillusionment, injustice, inflicted cruelty, and abasement for having to give in, whirl within us but yet there is no possible outlet of expression" (14).

- People gradually lose their ideals and faith in government. They accept that no good can be expected from the civil services. The **social conscience grows numb** (5,14)**.**

- Alarming is that in a corrupt society **victims become corruptors**. You learn what you live. Victims thus become part of the system. If victims later in life come into charge, they also abuse their power.
  This phenomenon is well known and studied in psychology: for instance, most children who receive cruel treatment at home, will later be cruel to their own offspring.
  A corrupt nation hereby creates an increasing number of perpetrators (14,19)**.**

V.6 JUSTIFICATION OF CORRUPTION

In a corrupt nation there is commonly only a small minority that openly criticizes corruption.

In contrast, the corruptors try to make people accept corruption. To excuse or justify corrupt practices they use the following contradictive arguments:

- Corruption is an Asian tradition that dates back to ancient Asian societies, in which it was custom to offer gifts to officials. What happens now is only a continuation of this practice of the past.
  However they forget that in the past side by side with the gift custom corruption existed, and corruption thus did not evolve from it.

- Corruption is a creation of the West, forced upon Asia during colonization.
  Corruption is not a creation of Western colonization; it is documented that both ancient Asian and Western societies were affected by it.

- Asian history shows different norms and public morality.
  The occurence of corruption in Asia is a violation and not an expression of the norms and public morality. The teachings of Hinduism, Buddhism and Islam all condemn corruption.

- Corruption helps economic development and efficiency.
  In a corrupt developing country, the fittest who survives is not necessarily the most efficient and competitive. This has a negative impact on the national economy.

Among social scientists, nobody encourages and promotes corruption as an ideal. Some investigators do see some benefits and therefore tolerate it, yet no person recommends it for development. Corruption does however develop exploitation, inequality and moral and legal disorder (14).

V.7 PREVENTION OF CORRUPTION

For developing countries, corruption will stay the most important problem for a long time.

Eradication of corruption is not simply a matter of designing a strategy. It is a complicated fight against the corrupt, who cannot be seen but who do defend their position and oppose measures against corruption.

The effort to prevent corruption in the past was not effective apparently. One should try not to cover the same ground again and again**.** Nevertheless, attempts to oppose injustice and decrease the harm should not cease, however limited their results may be.

Let us look more closely at important factors in the fight against corruption:

- The most important factor is **high morality and integrity of the leaders** of society. Corrupt leaders cannot be expected to eliminate corruption. Honest leadership can change the conduct of subordinates.

  Chinese philosophers wrote in the 2nd century B.C. to the first Han Emperor:

  "If the ruler is sincere and upright, then honest officials will serve in his government and scoundrels will go into hiding, but if the ruler is not upright then evil men will have their way and loyal men will retire to seclusion"(14).

  Thus the rulers breed their own type: if the corrupt type is multiplied, all positions of power will be taken in by them. This proves to be extremely hard to alter. Only a revolution by the right moral type might bring a solution. But even a victorious revolution will face great difficulties controlling corruption, because also the right moral type, which earlier was not in the position to exploit power, will do everything to maintain control.

- Power corrupts. The greater the power of rulers, the more corrupt and criminal they become. With a progressive **restriction or decentralisation of power**, corruption of rulers tends to decrease. Thus democratic governments are less criminal than autocratic ones.

- **Strong leadership** is necessary. History mentions cases in which a leader was not corrupt, but all his employees were. In order to eradicate corruption such a leader is even worse than a corrupt one, as a false sense of security is spread and public resentment not provoked. Meanwhile the corruptors are not hindered in their malpractices. Such a leader is weak.

- **Rational and efficient laws** to prevent corruption.

- No structural or legal changes designed to fight corruption will succeed, unless there is a **sufficient number of individuals of high principle, personal quality and integrity** managing these changes.

- **Severe punishment of the corrupt.** The corrupt should know that punishment is harsh and that it will be applied with full force. Severe punishment can also change the public hesitation to come forward.

- Installation of **anti- corruption institutions**. Obviously the will to do so in a corrupt country is lacking. Besides, in the past corruption grew stronger within institutions intended to prevent corruption. Thus unless the employees have the right moral, these anti-corruption-institutions will also be abused and corrupted. Sometimes these systems merely function as window dressing, dealing only with small cases of corruption. They are often not independent but supervised by the powerholders. Despite their doubtful effectiveness, they can keep the effort alive.

- **Religion** can be used to make people aware of the problem of corruption. In Buddhism, Hinduism and Islam, corruption is as much condemned as stealing, cheating and killing and this should be emphasized. Religion can inspire to

hold on to moral values. Their relevance to contemporary problems as corruption is tremendous.

- The influence of **charismatic and sacral personalities** becomes important when leaders, courts and police are corrupt, indifferent and abuse their power. If society does not offer recourse to civilians, then the sacral personalities, who do not strive for power and wealth, can stimulate to maintain the ideals of rectitude. It is not important if they are dead or alive. Their lives and teachings inspire toward moral values. The inspiration provided by charismatic individuals has been decisive in great historical changes, such as the French and Russian Revolution.

- As poverty can increase corruption, some suggest that a **salary raise** of public servants can reduce their corrupt acts. Others belief that even if they are forced to stop their corrupt practices, public servants will not turn into saints overnight and will find new ways for illegally gaining wealth.

- Relying on government-initiated action against the corrupt is not an option, as the government itself is corrupt. It is therefore necessary to **wake up public awareness** of the problem, and an **anti-corruption mentality and behavior** should be created. People should not keep silent but generate pressure. **The press** can have a vital role in this. Propagation of collective shame and outrage is crucial. Besides news items, also analytic and investigative reports should be published. For the press to be really effective, freedom of expression and journalists with high morality are needed. In Indonesia the press has no freedom of expression and many journalists are also corrupt.

Measures against corruption should not be taken in isolation. The combined approach is the only promising one (14,15,18,19).

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Twenty years from now you will be more disappointed by the things you did not do than by the ones you did do. So throw off the bowlines. Sail away from the safe harbour. Catch the trade winds in your sails. Explore. Dream. Discover.

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Happiness is not a station you arrive at
but a manner in which you travel

VII. CURRICULUM VITAE

I was born in the Netherlands. With my parents and brother I lived part of my childhood in Saudi-Arabia. During this period the family travelled through Asia, the Middle-East, America and Canada. At the age of 8 years I visited Indonesia for the first time. I obtained my VWO diploma at Bonhoeffer College in Castricum. At Vrije University in Amsterdam I received my psychology propedeutics cum laude, and also my medicine propedeutics, doctoral and MD degrees. I did a traineeship in pediatrics in Canada and performed research in South-Africa on tuberculosis in children residing in townships. I travelled around the world with my partner and visited India, Australia, New Zealand and Mexico. Prof.dr. Veerman and prof.dr. Sutaryo offered me the opportunity to perform a pilot-study on compliance with childhood leukemia treatment in Indonesia. Afterwards prof.dr. Veerman invited me to design and write a research protocol and apply for a PhD program sponsored by the Dutch Cancer Society "Koningin Wilhelmina Fonds (KWF)." We received the grant and prof.dr. Sutaryo introduced Mei Neni Sitaresmi as my "Indonesian twin." Herewith our PhD-twinning-collaboration and friendship started. We received two SIOP awards and an award from KWF. Numerous editors approached us to write articles about our twinning project for their medical journals. My international background and upbringing in an Islamic country certainly have helped me to understand Indonesian society. It has been a privilege and joy to combine this research with living for two years in the Carribean with my partner and raising our four children. All this would not have been possible without the loving support of my parents and partner to whom I am grateful.

Saskia Mostert

There is sacred
in the ordinary

VIII. WORDS OF GRATITUDE

First and foremost I would like to express my gratitude to my supervisors prof.dr. A.J.P. Veerman and prof.dr. Sutaryo for offering me the opportunity to conduct research in Indonesia. I have sincerely appreciated the fact that you allowed Mei and me to write critical reports about our twinning project. The large response from doctors in other developing countries showed that health-care providers recognized the difficulties we faced. We received appraisal for describing reality.

Prof.dr. A.J.P. Veerman, I have highly appreciated the support, motivation and freedom you gave me. You showed faith in our work and always had shrewd remarks that offered new insights and helped to improve our studies. I am thankful that you allowed me to write manuscripts at home, either in the Netherlands or in the Carribean. You are loyal and dedicated to your outreach program.

Dear Mei, I want to thank you for being such a kind person and such a driven PhD twin. We have been a very good team. We supplemented and encouraged each other. I truly appreciated that you and your family took so good care of me during my stays in Yogyakarta. I will also not forget how nice it was to share experiences at either the Dr Sardjito Hospital or the VU University Medical Center and hotelrooms during our congress visits.

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I would also like to mention dr. Nulda Beyers, my supervisor on my first scientific project at the University of Stellenbosch in South-Africa. She has been an inspiration to me, and showed me how much fun it is to work in a dedicated team and perform research. She looked after children with tuberculosis from poor socio-economic backgrounds and taught me that it is very important to combine medicine with social work. I will never forget this lesson.

During the first half year that I lived in Yogyakarta I met some special friends: Jane, Paul and Michelle. They followed a language course in Yogya, before moving to Jakarta in order to work at the British and Australian embassies. It was wonderful to discover Yogyakarta together with you and I still remember the interesting conversations we had. During my later visits to Yogyakarta you invited me to stay over at your houses in Jakarta and we had a splendid time. Thank you.

When it comes to family, I look more like an Indonesian than a Westerner:

First I want to mention the respect and thankfulness I feel for my grandparents, oma and opa Helder and oma and opa Mostert, who have been so kind, positive, strong and loving to me as I grew up. Although they are no longer here, I carry them around in my heart.

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